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Experiences and Health Outcomes of Emerging Adults with Type 1 Diabetes: A Mixed Methods Study

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Abstract

Background. Emerging adults with type 1 diabetes are at risk of poorer diabetes-related health outcomes than other age groups. Several factors affecting the health and experiences of the emerging adults are culture and healthcare specific.

Objectives. The aim of this study was to explore the experience of emerging adults living with type 1 diabetes in Lebanon, describe their diabetes self-care and diabetes-related health outcomes (HbA1c and diabetes distress), and identify the predictors of these outcomes.

Methods. A convergent mixed methods design was used with 90 participants aged 18-29 years. Sociodemographic, clinical data, and measures of diabetes distress, social support, and self-care were collected. Fifteen emerging adults participated in individual semi-structured interviews. Multiple linear regression was used to determine predictors of diabetes outcomes. Thematic analysis was used to analyze qualitative data. Data integration was used to present the mixed methods findings.

Results. The study sample had a mean HbA1c of 7.7% (*SD*=1.36) and 81.1 % reported moderate to severe diabetes distress levels. 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 diabetes self-care; while diabetes distress was predicted by diabetes knowledge, blood glucose monitoring approach, and diabetes self-care. "Living with type 1 diabetes during emerging adulthood: the complex balance of a chemical reaction" was the overarching theme of the qualitative data, with three underlying themes: "Breaking of bonds: changes and taking ownership of their diabetes", "The reactants: factors affecting the diabetes experience", and "Aiming for equilibrium". The integrated mixed methods results revealed one divergence between the qualitative and quantitative findings related to the complexity of the effect of received social support.

Discussion. The suboptimal health of the emerging adults despite good self-care highlights the importance of addressing cultural and healthcare specific factors such as diabetes knowledge and public awareness, social support, and availability of technology to improve diabetes health. Findings of this study can guide future research, practice, and policy development.

Keywords: type 1 diabetes, emerging adults, transition, diabetes-related health, diabetes self-care

Experiences and Health Outcomes of Emerging Adults with Type 1 Diabetes: A Mixed Methods Study

Emerging adulthood is a distinct period spanning between ages 18 and 29 years, during which individuals demand more autonomy from their parents and are more likely to engage in risky health behaviors (Arnett, 2000). In the context of type 1 diabetes (T1D), emerging adults (EAs) start assuming more responsibility for their complex diabetes management (Ramchandani et al., 2019). However, studies have shown suboptimal diabetes self-care behaviors during this period (Montali et al., 2022; Ramchandani et al., 2019). EAs have worse glycemic levels (McKnight et al., 2015) and higher diabetes distress levels (Lašaitė et al., 2016) than any other age group living with T1D. Thus, the transition into adulthood is a major health concern for people living with T1D.

The main factors that influence the health of the EAs with T1D include diabetes knowledge and transition into adult healthcare preparation, self-care behaviors, and social support (Pyatak et al., 2017; Vallis et al., 2018). Transition preparation and education by the healthcare team can result in improved self-care (Kelly et al., 2018). However, healthcare support and self-management preparation often do not match the developmental needs of the EAs and are not provided systematically (Joly, 2015). Consequently, diabetes self-care practices of EAs with T1D are often suboptimal. Social support is another pivotal aspect that affects the health of EAs with T1D (Joly, 2015). The literature on social support underscores the changing nature of the relationship between the individuals with T1D and their parents and peers during emerging adulthood, and the influence of this change on their diabetes-related health (Campbell et al., 2019; Kelly et al., 2018; Vallis et al., 2018). Despite the positive effects of parental support on the health of their children (Kelly et al., 2018), parental conflict and over- or under-involvement of parents in the care of the EAs reflect poorly on their disease management and health outcomes (Campbell et al., 2019). On the other hand, the findings on the effect of peers, which is significant in this period, on the EA's behavioral and diabetes-related health are not consistent (Wiebe et al., 2018).

Research on the EAs with T1D is mostly conducted in Western cultures. Although the prevalence and treatment of T1D may be similar in various countries, the different healthcare and cultural contexts are likely to affect how EAs respond to and manage their illness. For instance, it is customary for adult children in Lebanon to reside with their parents until marriage. Thus, there is a prolonged involvement of the nuclear family in the management of the children's illnesses (Shideed et al., 2013). There is very limited research on the effect of ethnicity and culture on living with T1D, especially during the different developmental stages (Butler et al., 2017). To the best of our knowledge, this was the first study in Lebanon and the Middle East and North Africa (MENA) region that explored the experiences of EAs living with T1D and the factors associated with their diabetes-related health.

This study was guided by the Transitions Theory (Meleis et al., 2000). The Transitions theory describes what happens during (any) transition, including the developmental transition into adulthood. During transition, changes in an individual's life cause instability, affect health, and can lead to delayed or ineffective coping. A successful transition leads to well-being and a reformulated identity (Meleis et al., 2000).

A mixed methods approach was used to explore the experience of EAs living with T1D in Lebanon and describe their diabetes-related health. The specific aims of the quantitative arm of the study were to 1) describe the self-care practices, social support, incidence of acute diabetes complications (severe hypoglycemia and diabetes ketoacidosis), and diabetes-related health outcomes (HbA1c and diabetes distress) of the EAs, 2) investigate the associations between sociodemographic/ clinical variables and self-care practices, and 3) determine the predictors of the diabetes-related health outcomes. The aim of the qualitative arm of the study was to explore the changes that the EAs are passing through during their transition into adulthood, their perceived challenges, and the available support systems during this period. Finally, the aim of the mixed methods approach was to explain and interpret the quantitative results using the qualitative data about the experiences of the EAs with their challenges and support systems.

Methods

Study Design and Sample

We used a mixed methods concurrent convergent triangulation design, with a cross-sectional quantitative and a descriptive qualitative approach. The quantitative and qualitative data were merged during interpretation, to provide a comprehensive understanding of the findings (Fetters et al., 2013).

Convenience sampling was used for the quantitative arm to recruit participants who met the following inclusion criteria: age between 18 to 29 years and diagnosed with T1D at least one year before turning 18 years. Exclusion criteria included diagnosis of T1D with other chronic conditions, and pregnancy. The sample included 90 EAs with T1D. Participants were recruited from the pediatric and adult diabetes clinics of a referral medical center in Lebanon. The clinics' diabetes care and education specialist identified 67 eligible participants and invited them to participate in the study; 48 EAs agreed to participate, and their contact information was shared with the researcher. The remaining participants were recruited through social media platforms (*n*=25) and snowballing technique (*n*=17). A nested purposive maximum variation sample of participants who completed the survey and consented to be interviewed were recruited for the qualitative interviews. Due to COVID-19 restrictions, all data were collected virtually through Zoom or WhatsApp video calls in a quiet, private place. Data collection ran over five months (August – December 2021). Participants received a participation incentive.

Sample size for the quantitative arm of the study was estimated based on running two multiple linear regression analyses on the study outcomes (HbA1c and diabetes distress). Studies that included linear regressions on those two outcomes had estimates of effect size (R^2) ranging between 0.24 – 0.51 (Garvey et al., 2012; Law et al., 2012; Majumder et al., 2016; Stahl-Pehe et al., 2019). Assuming the smallest reported effect size (0.24), 80% power, and a significance level of 0.025, the minimum sample size needed was 90. Sample calculation was done using GPower version 3.0.10. The qualitative study sample included 15 participants, with the sample size determined by reaching data saturation.

The study was approved by the Institutional Review Board of the American University of Beirut where the study was conducted (IRB ID: SBS-2021-0109). All participants provided their verbal informed consent to participate in this study. All data were de-identified, coded, and stored in a password-protected computer.

Quantitative Study Methods

Data were collected through individual interviews conducted virtually through Zoom or WhatsApp video calls, as per COVID-19 pandemic restrictions. During the meetings, the participants were asked questions from a structured survey that had four sections measuring: sociodemographic/ clinical data, diabetes social support, diabetes self-care, and diabetes-related distress.

Sociodemographic and Clinical Characteristics

Sociodemographic information included age, gender, level of education, social status, and living arrangement. Clinical data covered smoking and alcohol consumption, time since T1D diagnosis, treatment type, clinic visits, HbA1c, and the number of diabetes ketoacidosis (DKA) episodes and severe hypoglycemia events during the last six months.

Social Support

Social support was measured by the Social Support subscale of the Diabetes Care Profile (DCP-SS) (Fitzgerald et al., 1996), a 19-item self-report measure that includes a Global social support subscale and two subscales measuring desired social support (WANT) and received social support (GET). Each item is measured on a Likert scale with lower scores indicating less diabetes-related social support. In this study, only the GET and Global questions were included in the analysis since these reflect the actual social support received by the EAs. The DCP-SS subscale was translated into Arabic and used in a prior study (Cronbach’s alpha [α] =.88; Sukkarieh-Haraty & Howard, 2015).

Diabetes Self-care

Diabetes self-care was measured by the 15-item Self-Care Inventory-Revised (SCI-R) tool (Weinger et al., 2005). The tool evaluates individuals' perceptions of how often they perform their diabetes management tasks on a five-point Likert scale. Scores are averaged and converted to a 0- to 100-point scale. The Cronbach's α was reported at .87 (Weinger et al., 2005).

Diabetes Distress

Diabetes distress was measured by the 28-items Type 1 Diabetes Distress Scale (T1-DDS) that measures diabetes-related emotional distress in adults with T1D with seven subscales (management, hypoglycemia, negative social perceptions, physician, eating, and family/friends distress) (Fisher et al., 2015). Participants rate the degree to which they find each item to be problematic on a six-point Likert scale. A mean score is calculated, and distress levels classified as 1.0-1.4 = little or no distress, 1.5-1.9 = mild, 2.0-2.9 = moderate, and ≥ 3.0 = high distress, with a cut-point score of 2 or higher reflecting clinically meaningful distress levels. The T1-DDS Cronbach's α was reported at .91 with good validity testing results (Fisher et al., 2015).

The SCI-R and the T1-DDS scales were translated into Arabic using the back translation method (Wild et al., 2005). A panel of experts assessed the conceptual relevance and cultural appropriateness (content validity) of the translated tools. The item content validity index (I-CVI) and the overall scale content validity index (S-CVI) were calculated. The Arabic versions of the SCI-R and T1DDS had cultural appropriateness scores per item ranging between 0.8 and 1, and their overall S-CVI scores were 0.8 and 0.89, respectively. The SCI-R had conceptual relevance scores per item ranging between 0.8 and 1 whereas the T1DDS items all scored 1; the overall S-CVI score of the SCI-R and T1DDS were 0.73 and 1, respectively. No changes were recommended to the translated tools. The final survey was pilot tested with five EAs from the study population, and no changes were recommended. Data from the pilot test were not included in the main study analysis.

In this study, measures of the DCP-SS scale, SCI-R, and the T1DDS tools yielded high internal consistency, with Cronbach's α values of .72, .77, and .92, respectively.

Quantitative Data Analysis

Descriptive statistics (means and standard deviation, median and interquartile range, or frequency and percent) were used to describe demographic and clinical characteristics and other variables of interest. Bivariate analyses depending on the level of measurement (independent sample t tests, Pearson r correlation coefficient, Mann Whitney, Spearman Rho coefficient, Kruskal Wallis, and chi-square analyses) were conducted to test associations between the study variables. Two linear multivariable regression analyses were run to determine the predictors of the HbA1c and diabetes distress. As this is an exploratory analysis, all variables with a $p < .2$ at the bivariate level were simultaneously entered into the multivariable linear regression model (James et al., 2013). All statistical analyses were carried out using IBM Statistical Product and Service Solution (SPSS) version 26, with the statistical significance level at two-sided set at α =.05.

Qualitative Study Methods

Semi-structured individual virtual interviews were conducted and audio-recorded using an interview guide that included questions related to the changes in their self-care practices as they moved into adulthood, what challenges did they face, and what support systems were available to them during this period. The interview guide was developed by the research team and tested with two participants to ensure its clarity and comprehensiveness. The responses were used to finalize the interview guide questions and were not included in the analysis (see Supplemental Digital Content [http://links.lww.com/NRES/A532], S1).

Qualitative Data Analysis

Since this study was inspired by theory, thematic analysis approach was used accounting for the components of the study's conceptual framework. (Braun & Clarke, 2006). The six phases of thematic analysis were followed to generate the final thematic map (Braun & Clarke, 2006). To ensure rigor of results, a codebook was developed with definitions and examples of the conceptual components, to guide the analytical process (SDC S2). The data were hand-coded to facilitate a deeper immersion in the data. Data saturation was determined when no new information was found that added to the understanding of the categories or themes. Trustworthiness of the findings was ensured by employing measures to enhance the credibility, transferability, dependability, and confirmability of the data (for a description of measures is see SDC S3).

Mixed Methods Data Integration Approach

Following separate analyses of the quantitative and qualitative data, the results were interpreted using a “themes-by-statistics” type of joint display. This allowed for a comprehensive understanding of the findings by explaining the convergence or divergence of the quantitative and qualitative data (Guetterman et al., 2015).

Results

Quantitative Results

Sample Characteristics

No variable had a missing data > 5%. More than half the sample were female (61%) and single (88.9%), with a mean diabetes duration M = 10.3, SD = 4.6 years (Table 1). Almost all the participants (94.4%) were living with their parents or spouse. The majority (86.7%) were on multiple daily insulin injections, and 13.3% used insulin pump therapy. More than half (63.3%) used a glucometer and 36.7% used a continuous/flash glucose monitoring device. Around two-thirds (65.6%) reported receiving diabetes management education, and only 56.7% rated their diabetes knowledge as “excellent” or “very good” on a Likert scale from 1 to 4.

Diabetes-Related Characteristics and Outcomes

The participants had a median HbA1c level of 7.7% (IQR 6.6–8.4), with 70% having HbA1c levels above the recommended target of ≥ 7%. The mean diabetes distress score was high (M = 80.4, SD = 25.6), with most of the participants (81.1%) experiencing at least moderate distress levels. Half of the participants reported at least one acute diabetes complication (severe hypoglycemia/ DKA) during the past six months. The mean score of self-care was 69 (SD = 13.4) out of 100. The median score of social support was 48 (IQR 41–53.3) out of 60 (Table 1).

Associations between Sociodemographic/ Clinical Variables and Self-care

Participants who had fewer 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, $p = .041$). Moreover, participants who received a formal diabetes education had higher diabetes self-care scores than those who did not (71.4 vs. 64.5, $p = .018$). Likewise, diabetes management knowledge was positively associated with self-care scores ($r = .26$, $p = .013$).

Predictors of Diabetes-Related Health Outcomes

The bivariate analyses revealed some significant associations between the study variables and diabetes outcomes (HbA1c and diabetes distress; all bivariate analyses are found in SDC S4). With HbA1c as the outcome, the regression model (Table 2) was significant, with an adjusted $R^2 = .21$, $F(5, 83) = 5.551$, $p < .001$. Lower HbA1c levels were predicted by using insulin pump therapy, being diagnosed at an older age, and higher self-care scores.

With diabetes distress as the outcome, the regression model (Table 3) was significant, with an adjusted $R^2 = 0.27$, $F(7, 83) = 4.372$, $p < .001$. A lower diabetes distress score was predicted by higher diabetes knowledge, using continuous/ flash glucose monitoring devices, and higher self-care scores.

Qualitative Findings

The participants of the qualitative arm of the study ($n = 15$) had sociodemographic and clinical characteristics similar to those of the overall study sample. The data revealed three themes and eight subthemes that were subsumed under the overarching theme: “Living with T1D during emerging adulthood: the complex balance of a chemical reaction”. The first main theme, "Breaking of Bonds: Changes and Taking Ownership of their Diabetes," encapsulates the cognitive and attitudinal shifts experienced by all participants as they began to take control of their diabetes management. This theme includes two subthemes: assuming more responsibility and demanding autonomy. As EAs transitioned into adulthood, they consciously and spontaneously took on more diabetes-related responsibilities that were previously managed by their parents. This shift signifies a pivotal moment where the EAs felt grown-up enough to handle their condition independently. Alongside this increased responsibility, EAs also demanded greater autonomy, actively seeking to reduce their parents’ involvement in their daily diabetes care. This desire for independence was driven by their need to assert control over their lives and health decisions, highlighting a significant developmental milestone in their journey towards adulthood.

The second theme, "The Reactants: Factors Affecting the Diabetes Experience," identifies three major factors that influence the diabetes experience of EAs: the emerging adult, the community, and the society. Changes in personal characteristics, such as improved self-care and increased knowledge of diabetes management, were prominent during this developmental stage. Moreover, community support from parents, peers, and healthcare providers played a crucial role in managing the disease and providing emotional support. Parental support often persisted even as EAs sought more independence, while friends with diabetes offered empathy and practical advice that friends without diabetes could not. However, societal stigma remained a significant challenge, with participants facing varying degrees of discrimination and misunderstanding about their condition, ranging from pity to outright discrimination in the workplace. These three factors interacted continuously, shaping the overall experience of living with diabetes for EAs.

The third theme, "Aiming for Equilibrium," describes the participants' efforts to find balance in their lives while managing diabetes. Coping strategies included normalizing diabetes as a part of daily life and accepting it as a constant companion. This acceptance was crucial for feeling situated within their communities. However, persistent diabetes-related stress remained a significant issue, evoking emotions like anger, frustration, and burnout, especially exacerbated by the COVID-19 pandemic. Participants expressed a range of wishes and needs to help them achieve better equilibrium. These included desires for reduced parental overprotection, greater societal awareness about diabetes, and more comprehensive mental health support from healthcare professionals. These unmet needs highlight the areas where additional support and resources could significantly enhance the well-being of EAs managing T1D. These themes and subthemes are explained and supported by excerpts from the participants and presented in Table 4. Further information about the themes, subthemes, and categories is available in SDC S5.

Mixed Methods Results: Data Integration

The integrated interpretation of the findings is presented as a meta-inference. Quantitative results, such as the mean scores of the diabetes distress scale and its subscales, the social support and self-care scales, were examined against themes and subthemes from the qualitative findings. For instance, the distribution of scores of the T1-DSS was examined against the persistent diabetes stress subtheme that transpired from the qualitative interviews and supported the relatively high score. Overall, the qualitative findings concurred with the quantitative results, with one exception related to the participants’ experiences of the social perception around diabetes. Despite the low score on the negative social perception subscale, some participants in the qualitative interviews reported feelings of anger and frustration from diabetes stigmatization. These integrated findings are detailed in the “themes-by-statistics” joint display of integrated analyses (Table 5).

Discussion

The study examined the experiences of 90 EAs living with T1D in Lebanon and how the transition into adulthood affected their diabetes self-care practices and health outcomes. Our findings highlight the suboptimal diabetes-related health of the EAs, as reported in prior studies (McKnight et al., 2015), with 70 % of the participants having HbA1c levels above the recommended target. Other investigators reported higher HbA1c levels than in our sample (Zoffmann et al., 2014), which might indicate better glycemic management among our participants, despite not meeting the target HbA1c. This finding might be an effect of the COVID-19 pandemic as reflected by the qualitative findings, whereby some participants stated that they were vigilant about monitoring their blood glucose so as not to get sick and require hospitalization because of the pandemic. This finding comes in line with other research that highlighted the pandemic's inadvertent positive influence on glucose levels, driven by individuals' concerns about the potential adverse effects of COVID-19 on their health (Fernández et al., 2020).

The participants reported higher diabetes distress levels in this study than in others (Downie et al., 2021; Lašaitė et al., 2016). The qualitative findings suggested that the psychological effect of diabetes could be attributed to feelings of anger and frustration due to perceived diabetes stigmatization, fearing for their future, and a sense of diabetes burnout. Perceived diabetes-related stigma has been noted to lead to negative perceptions of having diabetes and increased stress among adolescents and young adults with T1D (Montali et al., 2022; Soufi et al., 2024). Diabetes burnout is also associated with diabetes distress (Helgeson, 2021). The elevated scores might also be attributed to the COVID-19 pandemic, which has been linked to deteriorating psychological health outcomes in EAs with T1D, primarily due to health-related anxieties prompted by the pandemic (Tejera-Perez et al., 2021). It is worth noting that the lack of mental health care available for the participants could have contributed to the high distress levels. The participants alluded to this gap in care and requested to integrate mental health care into their treatment.

Factors associated with diabetes-related health in this study included diabetes self-care, diabetes knowledge, and the use of diabetes technology (such as insulin pump therapy and continuous/ flash BG monitoring devices). The positive association between self-care and diabetes health outcomes is in line with the literature (Pyatak et al., 2017; Vallis et al., 2018). However, this study demonstrated unique integrated results in terms of self-care behaviors of the EAs. Contrary to the worsening self-care documented during emerging adulthood (Ramchandani et al., 2019), our findings showed adequate self-care practices by the participants. This finding may be explained by the participants' concern regarding the effects of COVID-19, as noted in a prior study (Aragona et al., 2020). Another factor in this sample is the use of diabetes technology as it provided flexibility and reduced diabetes management burden. Prior studies have shown that the use of diabetes technology promoted blood glucose control, facilitated self-care practices, and reduced diabetes-related anxiety (Bayrakdar et al., 2014; Los et al., 2016). However, as noted in this study, the utilization of diabetes devices remains suboptimal among the EAs with T1D population (Tanenbaum et al., 2017). Thus, EAs would particularly benefit from interventions that would increase their acceptance of and access to these devices. In addition, the findings highlighted the positive effect of diabetes management education on self-care practices, as reported in previous work (Joly, 2015). It is thus concerning to find that one-third of the participants reported not receiving such education from a health care worker, with 44% of them reporting only “good” or “fair” levels of diabetes knowledge.

The participants reported high levels of received social support, potentially accounting for the observed divergence in the integrated mixed methods results. Specifically, while participants reported experiencing stigma-related frustrations in the qualitative interviews, these reports did not correspond with the lower scores observed in the negative social perception subscale. There were two sources of social support for EAs, peers with diabetes and parental support. As in this study, the positive effect of the support of ‘peers with diabetes’ on the health of the EAs has been widely recognized (Montali et al., 2022; Ng et al., 2021). Parental support, on the other hand, was more complex, with the participants requesting autonomy and shying away from parental supervision, as noted in prior work (Johansen et al., 2020). Parental involvement in the care of the participants decreased during this period but was still pronounced. The low score of the “Want” (needed) social support subscale, which comes in contrast with the high scores of the “Get” (received) social support, indicates that participants wanted less support from parents/ family than what they were receiving. The qualitative findings validated these results as participants reported experiencing diabetes-related parental conflicts and wished for less parental involvement. When parental involvement is unsolicited, it hinders the EAs' successful mastery of adult roles, often leads to conflict, and has a negative emotional effect on the EAs (Johansen et al., 2020). In collectivist cultures as in Lebanon (Green et al., 2016), the effect of parental conflict is even more amplified due to the greater involvement of parents in the care of EAs than in individualistic cultures. Our findings suggest that it may be helpful if parents are more considerate of providing support in accordance with their children's wishes.

Limitations

The interpretation of the study findings should be viewed considering some limitations. A longitudinal design may be more appropriate to study the effect of emerging adulthood on diabetes outcomes than a cross sectional design. However, given the lack of studies on this topic in the MENA region, a baseline mixed methods approach is appropriate at this stage. Social desirability is a potential limitation related to the use of self-report questionnaires. Participants might have reported better self-care practices than what they performed, trying to demonstrate their independence and competence in managing their diabetes. Finally, the study was conducted during the exceptional time of the COVID-19 pandemic, which may have affected some of the findings in terms of increasing the distress levels among the participants.

Conclusions

The findings highlight the complexity of living with T1D in an understudied and vulnerable population, documenting the poor diabetes health of the EAs and associated factors. The findings fit the framework derived from the Transitions theory, showing that personal factors, the community, and the society affect the ability of the participants to achieve optimal health. The study findings add to global knowledge about EAs with T1D and add to regional knowledge about the need for better support for these patients from healthcare professionals and policy makers. Future research should include perspectives from stakeholders like parents and nurses to develop comprehensive interventions, while policymakers should focus on creating health policies that reduce stigma, integrate mental health care, and ensure diabetes technology treatment coverage. Additionally, nursing education programs need to emphasize providing tailored care to improve diabetes knowledge, self-care behaviors, and emotional well-being for individuals living with diabetes across the lifespan.

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Table 1

*Sociodemographic and Clinical Characteristics and Outcomes (*N=90*)*

Characteristics	*n*	%	*Mean* or *Median*	*SD* or (*IQR)*
Age (years)			21	(19–25)
Gender				
Female	55	61.0		
Social status				
Single	80	88.9		
Married / Engaged	10	11.1		
Level of Education				
High school level or less	5	5.6		
University	85	94.4		
Employment Status				
Unemployed/ Student	57	63.3		
Employed	33	36.7		
Smoking Status				
Non-smoker	61	67.8		
Consumes Alcohol	18	20.0		
Crowding Index			1	(0.75–1)
Two or more clinic visits during last year	65	72.2		
Insulin Treatment Type				
Glargine/Detemir/Deglutec + SAI	78	86.7		
Insulin Pump Therapy	12	13.3		
Glucose Monitoring Type				
Glucometer	57	63.3		
Continuous/ Flash glucose monitoring	33	36.7		
Received Diabetes Management Education	59	65.6		
Age at diagnosis in years			12	(9–16)
Diabetes duration in years			10.3	4.6
HbA1c Level (%)			7.7	(6.6–8.4)
DKA	4	4.4		
Severe Hypoglycemia	42	46.6		
Overall Diabetes Distress Score			80.4	25.6
Diabetes Distress Categories				
No / Mild Distress	17	18.9		
Moderate Distress	31	34.4		
High Distress	42	46.7		
Diabetes Self-Care Score			69	13.4
Overall Social Support Score			48	(41–53.3)
WANT Social Support Subscale			15	(11.7–20)
GET Social Support Subscale			22	(17.7–26)
Global Social Support Attitude Subscale			27	(25.7–30)

Note. SAI = Short acting insulin; Crowding index= number of people/number of rooms in a household; DKA = diabetic ketoacidosis

Table 2

Regression Model of the Predictors of HbA1c (N = 88)

Variables	B	t	p	95% CI
Insulin Treatment Type [a]	−1.02	−2.78	.007	−1.76, −0.29
Age at Diagnosis	−0.10	−2.50	.014	−0.19, −0.02
BG Monitoring [b]	−0.31	−1.20	.233	−0.82, 0.20
Diabetes Duration	−0.02	−0.50	.618	−0.10, 0.06
Self-Care	−0.02	−2.02	.046	−0.04, 0.00

Note. CI = confidence interval; BG = blood glucose.

[a] = Insulin Treatment Type: 1 = multiple daily injections, 2 = insulin pump therapy.

[b] = BG monitoring: 1 = glucometer, 2 = continuous/flash BG monitoring.

Table 3

Regression Model of the Predictors of Diabetes Distress (N = 90)

Variables	*B*	*t*	*p*	95% CI
Gender [a]	0.41	1.06	.581	−0.21, 0.92
Diabetes Knowledge	−6.11	−2.06	.042	−11.23, −0.65
BG Monitoring [b]	−10.90	−2.24	.028	−20.48, −1.22
Diabetes Education	−1.12	−0.19	.849	−12.82, 10.58
Crowding index	12.10	1.72	.089	−1.86, 26.03
Self-Care	−0.45	−2.28	.025	−081, −0.06
Social Support	0.17	0.51	.613	−0.51, 0.85

Note. CI = confidence interval; BG = blood glucose.

[a] = Gender: 1 = male, 2 = female.

[b] = BG monitoring: 1 = glucometer, 2 = continuous/flash BG monitoring.

Table 4

Qualitative Findings: Themes, Subthemes, and Exemplar Quotes

Themes/Subthemes	Description	Exemplar Quotes
Theme 1- “Breaking of Bonds: Changes and Taking Ownership of their Diabetes” Description: All participants experienced cognitive and attitudinal changes that encompassed breaking the diabetes-related ties with their parents and were looking forward to taking ownership of their disease. Two subthemes described this theme:		
Assuming More Responsibility	This subtheme reflects a conscious and spontaneous shift in diabetes-related responsibilities from the parents to the EAs.	*“Now I am a grown-up, so my parents have ‘given me the reins’. I took this ownership of having to deal with my diabetes on my own”. (G)*
Demanding Autonomy and Less Parental Involvement	The EAs demanded autonomy from their parents’ constant involvement in their daily diabetes care and shied away from parental supervision.	*“My parents do not have any role in my care… I reached an age where I am responsible for my diabetes. This was by my request, not theirs”. (F)*
Theme 2 – “The Reactants: Factors Affecting the Diabetes Experience” Description: This theme recognizes the three major reactants or factors that interact together in affecting the EA’s experience of living with diabetes (the Emerging Adult, the Community, and the Society):		
The Emerging Adult	Developmental transformations during emerging adulthood underpinned some changes in the personal characteristics of the participants. The main two changes included *changes in self-care* and *increased knowledge of diabetes management*.	*“I felt the need to take care of myself… I started testing my blood sugar, taking my insulin shot according to my meal and my sugar levels. I became responsible for everything related to my diabetes. I even go to my clinic visits by myself now”. (R)*
The Community	The community factor was reflected through the support that EAs received from their parents, peers, and their health care providers. Community support that came from different key people provided disease management and emotional support.	*“My parents would always say, ‘even if you are one hundred years old, we will still go with you to the doctor’s visit’”. (D)* *“My doctor does not have diabetes; she will not understand what I am going through… but my friends with diabetes understand and support me”. (R)* *“The healthcare team are my fort; they protect me as I walk through. The clinic visits set the path that I need to take for the next three months…” (S)*
The Society	Stigma from the society was evident and perceived at varying levels ranging from feelings of pity and lack of awareness about T1D to facing discrimination in the workplace.	*“I lost my job internship because of my diabetes… One day I woke up with a hypo... I told my supervisor that I am going to arrive late. She was rude to me and said ‘we don’t babysit here. If you’re sick, we don’t need you to come here’” (M).*

Theme 3 – “Aiming for Equilibrium” Description: The path to equilibrium for these EAs is akin to a roller coaster track, depending on the interplay between the reactants. The following subthemes describes how participants attempted to reach their equilibrium:		
Coping and Feeling Situated	Coping with diabetes necessitated changing their perception of diabetes in a way that normalizes it as a constant in their daily life. This process involved accepting diabetes and feeling situated in their community as people with T1D.	*“Diabetes is not easy to handle, but if you befriend it, you can live with it. I am very much at ease with it… If you don’t consider diabetes as your friend, you cannot continue your trip together, he will defeat you”. (Y)*
Persistent Diabetes Stress	Living with T1D resulted in a continued diabetes 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, especially during COVID.	*“Having diabetes is not shameful or pitiful. Some people when they see me doing my injection look at me with pity and it really bothers me, they make me feel like I am different”. (M)* *“Diabetes is a lot of hard work. It increases your mental load… it is a lot of pressure to manage it... I feel bad about myself when I don’t”. (L)*
Wishes and Needs	Participants reported wishes and needs for change from their parents, society, and healthcare professionals. These wishes and needs reflect the missing factors that will facilitate the participants reaching a state of equilibrium and promote good physical and mental health.	*“I would ask my parents to stop being overprotective and just support me and believe that I can do anything”. (L)* *“I wish there is more awareness about diabetes for people, parents, schools, friends… that we are human too”. (R)* *“I wish the healthcare team looked more into our mental health. It is always brushed aside. It’s not only about the medications and the numbers”. (S)*

Table 5

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

Quantitative Results	Qualitative Results		Meta-Inferences
	Themes and Subthemes	Excerpts	Mixed Methods Interpretation
Diabetes Distress			
Diabetes Distress score: 80.4 ± 25.6 (minimum-maximum 32–140), 34.4% had moderate distress levels, 46.7% had high distress levels	Aiming for a State of Equilibrium - Persistent diabetes stress	*I am always dealing with everything as if I am not good enough and I am not complete… Always thinking, what if diabetes ruins it…relationships, jobs, university, everything… what if I lose what I achieved or lose even this life because of this disease… (M).*	*Convergence* 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.
Family/ Friends Distress subscale score: 11.0 ± 5.2 (minimum-maximum 4–24). *Want Social Support score* 15.5 ± 0.6 (minimum-maximum 6-30)	Aiming for a State of Equilibrium - Coping and Feeling Situated	*My parents keep on nagging me about my diabetes. This sometimes puts a strain on my relationship with my parents, and that annoys me... (K)*	*Convergence* The “Coping and feeling situated” subtheme addressed how the diabetes-related over involvement interaction with family/ friends negatively affected the psychological coping of the participants. The was reflected by the moderately high 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/ friends in their diabetes management.
Management Distress subscale score: 11.4 ± 4.7 (minimum-maximum 4–24)	Aiming for a State of Equilibrium - Persistent Diabetes Stress	*Diabetes is a lot of hard work. It increases your mental load… it is a lot of pressure to manage it... I feel bad about myself when I don’t. (L)*	*Convergence* The “Persistent Diabetes Distress” subtheme represented how the participants were affected by the strenuous demands of managing diabetes and this converged with the high “diabetes management distress” subscale score.
Negative Social Perception subscale score: 8.7 ± 4.6 (minimum-maximum 4–24)	Aiming for a State of Equilibrium - Persistent Diabetes Stress Coping and Feeling	*Having diabetes is not shameful or pitiful. Some people when they see me doing my injection look at me with pity and it really bothers me, they make me feel like I am different. (M)* *When I tell people I have diabetes, I feel they start caring for me more. (K)*	*Divergence* Eight of the participants reported feelings of anger and frustration from diabetes stigmatization. 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

	Situated		participants received from their community.
Physician Distress subscale score: 8.5 ± 5.0 (minimum-maximum 4–24).	The Reactants: Factors Affecting the Diabetes Experience - The Community Aiming for a State of Equilibrium - Wishes & Needs	*The healthcare team are my fort; they protect me as I walk through. The clinic visits set the path that I need to take for the next three months… (S)* *I would ask to view the person coming to your clinic as a human with feelings and needs… Try to understand the psychological effect of living with this condition… it’s not only about the medications. (L)*	*Convergence* The “Reactants -Factors Affecting the Diabetes Experience” theme noted that the participants have a good relationship with their health care providers. Nevertheless, this did not negate the gap in care that some participants reported in the “Wishes & Needs” 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 Self-Care			
Diabetes Self-care scores 69 ± 13.4 (minimum-maximum 26 -96)	The Reactants: Factors Affecting the Diabetes Experience- The Emerging Adult	*I felt the need to take care of everything… I started testing my blood sugar, take my insulin shot according to my meal and my blood sugar test. I became responsible for everything related to my diabetes … (R).*	*Convergence* In the “Change in Self-Care” subtheme, the participants explained how their self-care skills and abilities improved during this period, which reflects the noted high scores of the diabetes self-care scale.
Significant positive association between self-care and attending ≥ 2 clinic visits (Mean score 64.4 vs. 70.8, *p*= 0.041) and receiving diabetes management education (71.4 vs. 64.5, *p*= .018)	The Reactants: Factors Affecting the Diabetes Experience - The Community	*The healthcare team gave me all the information that I need to know. So now, I am ready to be alone in managing these issues. (Y).*	*Convergence* Self-care scores were higher when the participants attended ≥ 2 clinic visits during the last year. The “Reactants -Factors Affecting the Diabetes Experience” theme clarified how the healthcare team provided the EAs with diabetes self-care education and support during their clinic visits.
Significant positive association between self-care and diabetes management knowledge (*r* = .26, *p* = .013)	The Reactants: Factors Affecting the Diabetes Experience - The Emerging Adult	*Around 3 to 4 years ago, I started taking better care of myself, I started to read more about diabetes, read about different insulin types, impact of food, glycemic index, protein, carbs, all those things… (S).*	*Convergence* The increased knowledge and changes in self-management that the EAs experience explain the improvement noted in their self-care practices. This went in line with the quantitative findings of higher knowledge associated with better self-care.
Social Support			
Social support subscale scores: Get score 21.0 ± 0.6,	The Reactants: Factors Affecting the Diabetes Experience - The	*My mom would sometimes change my insulin pen needle. Some days if I was very low [blood sugar], she would make me juice or something. Even*	*Convergence* The “Reactants: Factors Affecting the Diabetes Experience” theme noted the reluctance of parents to relinquish control

(minimum-maximum 6-30)	Community	*though I do not really need the help… (S).*	of their children’s diabetes management. This support was evident by the high scores of the received social support (GET scores). Likewise, in the “Wishes and Needs” subtheme, the participants reported a need for more autonomy and wished less involvement and more trust from their parents, which was reflected by the relatively low WANT scores of the social support scale indicating not wanting or needing support from family or friends.
Want score 15.5 ± 0.6 (minimum-maximum 6-30)	Aiming for a State of Equilibrium - Wishes & Needs	*I would have my parents worry less about me…, because now they worry all the time… and this stresses me out... (R).*	

Experiences and Health Outcomes of Emerging Adults with T1D: A Mixed Methods Study

Supplementary Material S1

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. How do you think your diabetes affects your life?
    a. Probe: academic/work life; family/social life?
4. 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?
5. 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…"

Supplementary Material S2

Table: Coding Framework

Question	Code	Definition of Codes	Examples
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 surrneder 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 still ask my 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.
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	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	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 becsaue it’s not really true …

healthcare team, what would you change?	from their parents, peers, and HCP	

Note. HCP = Health Care Provider

Supplementary Material S3

Reflexivity and rigor of the study

The Reflexivity and rigor were addressed Two research team members (SN) and (AB) addressed reflexivity of the researcher (AB) by performing periodic critical reflection of her position and values about the research. Trustworthiness of the study was achieved through establishing credibility, transferability, dependability, and confirmability [1]. The researchers attempted to ensure credibility through analysis triangulation and member checking. Two coders, (AB) and (SN), independently analyzed the same two transcripts, with inter-rater-reliability score of > 80% for both transcripts. Member checking was performed with three participants who stated that the analysis accurately reflected their perspectives. Dependability was achieved by having a researcher who is well-trained in qualitative interviewing conduct the interviews. Transferability was attempted by employing a purposive sample with maximum variation in age and gender. To verify confirmability, the researchers documented an audit trail of the decision process that took place throughout the stages of the study.

1. Lincoln YS, Guba EG. Naturalistic inquiry. Sage Publications; 1985.

Supplementary Material S4

Table: Associations of HbA1c and Diabetes Distress with Select Variables

	HbA1c		Diabetes Distress	
	Mdn (IQR) / correlation (r_s)	*p*	*M* ± SD / Mdn (IQR) / correlation (r)	*p*
Gender		.349		.095
Male	7.8 (7–8.3)		74.8 ± 24.1	
Female	7.5 (6.4–8.5)		84 ± 25.8	
Social Status		.200		.658
Single	7.8 (6.6–8.5)		80.8 ± 25.1	
Married/engaged	7.1 (6.1–7.5)		77 ± 29.3	
Living With		.275		.681
Family/ Spouse	7.8 (6.6–8.5)		80.6 ± 25.5	
Alone/ Friends	7 (6.3–7.5)		75.8 ± 26.9	
LOE		.951		.306
High school or less	7.8 (6.4–8.8)		69 ± 30.3	
University (current/ graduate)	7.6 (6.6–8.4)		81.1 ± 25.2	
Employment Status		.552		.640
Student/ Unemployed	7.8 (6.6 – 8.6)		81.4 ± 23.6	
Employed (Full-/ Part-time)	7.5 (6.9 – 8.1)		78.7 ± 28.6	
Treatment Site		.237		.587
Adult diabetes clinic	7.9 (6.8–8.5)		79.5 ± 25.5	
Paediatric diabetes clinic/ Family medicine clinic	8.0 (6.8–8.8)		87.2 ± 23.6	
Chronic Care Centre	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)	
BG Monitoring Type		.057		**.026**
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		**.024**		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

	HbA1c		**Diabetes Distress**	
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		**.030**
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**	**.003**
Age at Diagnosis	−.29**	**.006**	.08	.485
Diabetes Duration	.24*	**.022**	−.03	.815
Diabetes Management Knowledge	−.13	.226	−.29**	**.005**
Self-Care Score	−.29**	**.005**	−.29**	**.005**
Social Support Score	.09	.415	.14	.171

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

Supplementary Material S5

Table: 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) 1.2. Demanding Autonomy & Less Parental Involvement (N = 6)	1.1 The conscious and spontaneous shift in diabetes-related responsibilities from the parents to the EAs 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 2.1.1. Changing Self-Care (N = 13) 2.1.2. Increased Knowledge of Diabetes Management (N = 6) 2.2. The Community 2.2.1. The parents/ family members (N = 15) 2.2.2. Peers (N = 15) 2.2.3. Health Care Providers (N = 15) 2.3. The Society (N = 4)	2.1 The personal characteristics of the individual with T1D during emerging adulthood 2.2 The support received from parents, family members, friends, and the health care providers. 2.3 The society's role in providing or withholding a supportive environment.
3. Aiming for Equilibrium	3.1 Coping & Feeling Situated 3.1.1 Normalizing Diabetes (N = 9) 3.1.2 Diabetes Impact on Personal and Professional Life (N = 15) 3.1.3 Strength and Resilience (N = 5) 3.2 Persistent Diabetes Stress 3.2.1 Anger and Frustration (N = 8) 3.2.2 Fear for the Future (N = 3) 3.2.3 Diabetes Burnout (N = 5) 3.3 Wishes & Needs 3.3.1 From Parents/ Family (N = 15) 3.3.2 From Society (N = 11) 3.3.3 From Health Care Professionals (N = 15)	5.1 Coping through normalizing diabetes as a constant in their daily lives, and identifying as people with diabetes within their community. 5.2 The psychological responses of EAs living with T1D. 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, wishing for less stigma, and more focus on mental health.