



How does the mental health of caregivers affect diabetes management in adolescents with type 1 diabetes?

Diabetes caregiver mental health

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Abstract

Aim: The current study examined the impact of mental health status and socioeconomic conditions on diabetes management in adolescents with diabetes and their caregivers.

Methods: In this cross-sectional study, the Patient Health Questionnaire (PHQ-9) and the Hospital Anxiety and Depression Scale (HADS) were administered to adolescents over the age of ten who have had type 1 diabetes (T1D) for at least two years, along with their caregivers. The questionnaire results were assessed alongside the most recent HbA1c levels and the annual average HbA1c levels.

Results: A statistically significant and positive association was found between the average child's HbA1C and the parent's PHQ-9 score (Spearman's rho = 0.332, p=0.007), parent's HADS anxiety (Spearman's rho = 0.328, p=0.008), and HADS depression (Spearman's rho = 0.322, p=0.010) scores. There was also a positive and statistically significant association between the parent's PHQ-9 score (Spearman's rho = 0.291, p=0.020) and depression (Spearman's rho = 0.280, p=0.025) scores. However, no statistically significant association was found between the adolescents' average and last HbA1C levels and the PHQ-9, anxiety, and depression scores.

Conclusion: Parental mental health is as essential in the management of diabetes during adolescence as it is during childhood and should be evaluated regularly.

Keywords

mental health, type 1 diabetes, adolescent, caregiver

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Introduction

With its limitations and daily demands, type 1 diabetes mellitus (T1D) requires some parental adaptations. Parental adaptation has been identified as having a detrimental or protective effect on children's ability to cope with this condition.¹ With the recent interest in this aspect of the disease, many authors have focused on the mental health status of caregivers, who play an essential role in disease management.^{2,3} Due to the complexity of T1D management, multidisciplinary support is needed, with particular attention to patient and family psychology and emotions. Indeed, healthcare providers should be involved with parents, as T1D involves daily responsibilities such as blood sugar level assessments, insulin administration, and food intake regulation.⁴ Therefore, with this "extra work," difficulties in parent-child/adolescent interactions and increases in parental stress are reported by parents.⁵

Adolescence is when children seek independence while relying on their families for financial, emotional, and psychological support. Navigating this complex balance can be particularly challenging for adolescents with chronic illnesses, such as T1D, when it comes to managing their health. Many studies indicate that both younger and older adolescents with T1D often experience poor glycemic control and worse overall health outcomes.^{6,7} Previous research has shown that past and present family interactions and relationships impact the development of adolescents' self-care behaviors. Furthermore, parenting style and the alignment of family communication may influence glycemic control.^{8,9}

In this study, we assessed the influence of adolescent mental health and that of their primary caregivers on managing type 1 diabetes.

Materials and Methods

The study included 64 children aged 10 years and older who had been diagnosed with Type 1 diabetes for at least 2 years and their caregivers.

Height, weight, and BMI variables were standardized using standard deviation scores (SDS) based on Turkish norms.¹⁰ Pubertal development and breast and pubic hair growth were assessed using Tanner criteria.¹¹ After the examination, blood samples were collected from the patients to evaluate their HbA1c levels. The average HbA1c value was calculated by summing the four values examined over the last year and then dividing by four.

Before administering the questionnaire, we collected and recorded the sociodemographic characteristics of patients and their caregivers. This included information about the primary caregiver, marital status, employment status, educational background, the number of people living in the household, and the average monthly income, among other factors. Two pediatric endocrinologists in two different centers administered the Patient Health Questionnaire (PHQ-9) and the Hospital Anxiety and Depression Scale (HADS) questionnaires separately to the patient and caregiver.

The relationship between questionnaire results, sociodemographic data, the last glycosylated hemoglobin (HbA1c), and HbA1c averages in the previous year was evaluated.

Hospital Anxiety and Depression Scale (HADS)

HADS was designed to screen for the presence of anxiety and depression in patients with physical illness.¹² The Turkish validity and reliability study was conducted by Özdemir et al.¹³ The self-report scale consists of 14 items, 7 of which investigate depression and 7 of which investigate anxiety symptoms. Responses are evaluated on a four-point Likert scale and scored between 0 and 3.

The scale is designed to screen for anxiety and depression quickly to identify risk groups, not to make a diagnosis.

In preparing the score, 0-1 was accepted as "no risk," 2 score as "borderline disease risk," and 3-4 as "marked disease risk." The HAD scale has proven to be a helpful assessment tool, and score ranges minimize false positive or negative results (12). It has been shown that the score obtained from the scale is not affected by physical illness.¹⁴

Patient Health Questionnaire (PHQ-9)

The Patient Health Questionnaire-9 (PHQ-9) is a diagnostic tool designed to identify common mental disorders, such as depression, in primary care settings. Kroenke et al. validated it, measuring nine symptoms based on the PHQ-9 and diagnosing depression according to DSM-IV criteria.¹⁵ The short and straightforward nature of the questions is a significant advantage, making them easy to apply. Sari et al.¹⁶ carried out the Turkish reliability study of the questionnaire.

The questionnaire consists of 9 questions, each scored from 0 (never) to 3 (almost every day). The scores are added up for each question. According to the original questionnaire scoring system, scores between 1 and 4 are graded as minimal, 5-9 as mild, 10-14 as moderate, 15-19 as moderately severe, and 20-27 as severe depression. In addition to the nine diagnostic questions, the test includes one such question: "If you checked any problems, how difficult did they make it for you to do your job, take care of household chores, or get along with others?". However, this question does not affect the scoring.¹⁵

Ethical Approval

This study was approved by the Ethics Committee of Selçuk University (Date: 03.07.2024, Decision No: 341).

Statistical Analysis

All statistical analysis was performed using R version 4.2.1 (www.r-project.org) statistical software. Numerical data were presented as mean $\pm$ standard deviation (ranges: min – max), and categorical data were described as count (n) and percentage (%). Spearman's rho correlation coefficient was used to examine the relationship between HbA1c levels and PHQ-9 scores in children and parents. A two-tailed p-value less than 0.05 was considered statistically significant.

Reporting Guidelines

The study was reported in accordance with STROBE guideline.

Results

The mean age of the 64 study participants was 169.33 ± 27.97 months. Thirty-eight of the participants (59.4%) were male. The mean body weight of the participants was 54.52 ± 14.26 kg ($SD = 0.08 \pm 1.21$). Fifty-seven participants had completed puberty. The mean duration of diabetes in the patients was 5.63 ± 3.36 years. The participants' mean HbA1c values for the last year were 8.92 ± 1.83 , and the HbA1c at the previous visit was 8.85 ± 1.77 . The caregivers of 58 (90.6%) participants were their mothers. Only six children (9.4%) reported experiencing peer bullying due to their illness, while twelve children (18.8%) felt stigmatized. The general characteristics of the participants and the questionnaire results are shown in Table 1.

A statistically significant positive association was found between the average child's HbA1C and the parent's PHQ-9 score (Spearman's rho = 0.332, $p = 0.007$). Similar associations were observed with the parent's HADS anxiety (Spearman's rho = 0.328, $p = 0.008$) and HADS depression (Spearman's rho = 0.322, $p = 0.010$).

scores. There was also a positive and statistically significant association between the parent’s PHQ9 score (Spearman’s rho = 0.291, p=0.020) and depression (Spearman’s rho = 0.280, p=0.025) scores (Figure 1). However, no statistically significant association was found between the adolescents’ average and last HbA1C levels and the PHQ9, anxiety, and depression scores (Table 2). No considerable relationship was identified between HbA1c levels and the other sociocultural factors assessed.

Discussion

The results of this study identified a relationship between caregiver anxiety and depression and glycated hemoglobin (HbA1c)

levels, thus contributing to the existing literature by highlighting the importance of caregiver mental health in adolescent diabetes management.

A substantial body of literature shows cross-sectional and longitudinal associations between family and adolescent-level variables and glycemic control in younger and older adolescents.¹⁷ Family conflict related to diabetes, the perceived burden on parents, and a critical parenting style have been consistently linked to poor glycemic control.¹⁸ However, to resolve this complexity sensibly, there is no doubt that the mental health of the caregiver is also essential, and it will negatively affect diabetes management. In this study, a more substantial relationship was identified between

Table 1. General Characteristics of children and caregivers and questionnaire results

Characteristics	Statistics (n = 64)
Age, mo	169.33 ± 27.97 (120 to 216)
Sex (female/male)	26 (40.6)/38 (59.4)
Weight	54.52 ± 14.26 (24 to 89)
Weight SD	0.08 ± 1.21 (−2.70 to 3.60)
Height	158.18 ± 11.70 (125 to 179)
Height SD	−0.25 ± 0.98 (−2.60 to 2.93)
BMI	21.51 ± 3.97 (14.10 to 32.40)
BMI SD	1.28 ± 8.83 (−3.01 to 70.10)
Pubertal ≥stage 2	57 (89.1)
Number of siblings	2.73 ± 1.01 (1 to 6)
Number of people in the house	4.41 ± 1.00 (3 to 8)
Caregiver (father/mother/other)	3 (4.7)/58 (90.6)/3 (4.7)
Marital status of the caregiver (divorced/married/widow)	6 (9.4)/54 (84.4)/4 (6.3)
Caregiver’s employment status (housewife/worker)	47 (73.4)/17 (26.6)
Caregiver graduation degree (Primary/Secondary/College/Bachelor)	31 (48.4)/17 (26.6)/11 (17.2)/5 (7.8)
Family income (TL)	25 000 (10 000 to 100 000)
Experiencing peer bullying	6 (9.4)
Feeling stigmatized	12 (18.8)
Duration of diabetes (years)	5.63 ± 3.36 (1 to 15)
HbA1c average for the last year	8.92 ± 1.83 (6 to 13.2)
Latest HbA1c	8.85 ± 1.77 (5.1 to 13.3)
Patient’s PHQ-9 score	7.64 ± 4.64
Answers to the last question in PHQ-9	
It did not cause any difficulties	43 (67.2)
It created quite a difficulty	16 (25)
It created a lot of difficulties.	5 (7.8)
Patient’s anxiety score	6.05 ± 4.38
Patient’s depression score	3.88 ± 2.85
Caregiver’s PHQ-9 score	7.03 ± 3.74
Caregiver’s answers to the last question in PHQ-9	
It did not cause any difficulties	42 (65.6)
It created quite a difficulty	14 (21.9)
It created a lot of difficulties.	8 (12.5)
Caregiver’s anxiety score	8.02 ± 4.30
Caregiver’s depression score	5.39 ± 3.72

Table 2. The relationship between HbA1c and questionnaire Scores

	Average HbA1C		HbA1C	
	Spearman’s rho	P value	Spearman’s rho	P value
Child’s PHQ-9 score	−0.036	.780	0.064	.613
Child’s anxiety score	0.037	.771	0.095	.457
Child’s depression score	0.004	.974	0.060	.640
Caregiver’s PHQ-9 score	0.332	.007	0.291	.020
Caregiver’s anxiety score	0.328	.008	0.214	.090
Caregiver’s depression score	0.322	.010	0.280	.025

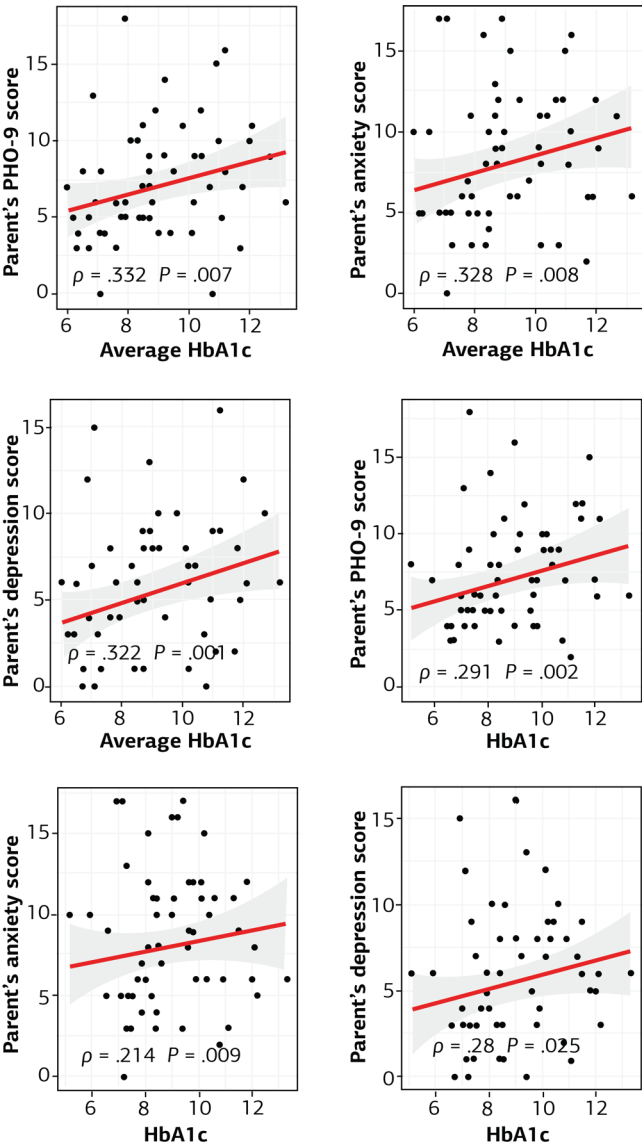


Figure 1. The relationship between average and last HbA1C and Caregiver's PHQ-9, anxiety, and depression scores

caregiver mental health and HbA1c than between the adolescents' mental health.

Studies have shown that individuals with lower socioeconomic status experienced more conflict with their children, less acceptance of diabetes, and increased parental stress; however, this status did not influence the level of parental monitoring of diabetes care.¹⁹ Participants in this study were generally of low economic status with similar socioeconomic levels. In other words, since the patients were a uniform group in terms of socioeconomic level, we believed that this factor did not act as an independent variable affecting HbA1c among them. Similar to the study by Silina et al., the data analysis failed to establish a statistically reliable relation between the child's environment and HbA1c or between socioeconomic factors in that circumference.²⁰

Many young people with diabetes face challenges related to self-esteem, body image, social roles, and relationships with peers. During adolescence, acceptance by friends and maintaining peer relationships are crucial. To avoid being seen as different by their peers, adolescents may use passive coping strategies, such as withdrawing, avoiding activities, and not adhering to their treatment plans.²¹ The stigma associated with chronic diseases is defined as negative social judgment based on the condition or its management. This stigma can lead to perceived or experienced exclusion, rejection, blame, stereotyping, and loss of status.

Adolescents and young adults may be especially vulnerable to stigma and its harmful effects during these life stages.²² Although studies are showing that stigma harms diabetes control by causing high HbA1c levels and more hypoglycemia, the number of patients who felt stigmatized and experienced peer bullying was very low among our patients.²³ There was no significant difference in HbA1c levels between patients who reported experiencing peer bullying or feeling stigmatized compared to others.

Studies have reported that fear of hypoglycemia, chronic sadness, and uncertainty are some common psychological responses for parents of children with diabetes, especially among mothers, and this may increase parental depression and anxiety, leading to higher HbA1c.²⁴ In our study, 90.6% of the caregivers were mothers. Thirty-one mothers had a HADS anxiety score above seven. As the anxiety and depression scores of caregivers increased, HbA1c levels also rose. Including fathers in the diabetes management process may reduce the stress burden on caregivers.

Limitations

The study has several limitations. Because it was a crosssectional study, causality could not be established, but the direction of the observed relationships remained unclear. Furthermore, the research relied on self-reported assessments of anxiety and depression, which may have introduced bias. Additionally, the study specifically targeted adolescents with T1D and their caregivers, meaning that the results may not be relevant to other age groups or types of diabetes. The limited sample size may impact how broadly the results can be applied. Despite these limitations, our study offers essential practical and clinical inferences. Improving caregiver mental health should be an important goal for families with an adolescent diagnosed with T1D, as this may lead to improved diabetes management.

Conclusion

In conclusion, the study suggests that caregiver mental health is essential to children's diabetes management outcomes. This highlights the importance of addressing mental health concerns in both children and their parents as part of diabetes care strategies. Diabetes is not solely an endocrine disorder; it also affects psychological and psychiatric health, the socioeconomic environment, and overall family functioning.

Diabetes care should be multidisciplinary, involving endocrinologists, primary care physicians, psychologists, psychiatrists, social workers, and other specialists. Fathers should also be involved in diabetes management, sharing the often overwhelming caregiver stress on mothers. It is important to note that working with parents is a critical component of interdisciplinary diabetes care, including preventive measures to improve mental health.

Declarations

Animal and Human Rights Statement

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Informed Consent

Written informed consent was obtained from all participants and their caregivers prior to inclusion in the study.

Data Availability

The datasets used and/or analyzed during the current study are not publicly available due to patient privacy reasons but are available from the corresponding author on reasonable request.

Conflict of Interest

The authors declare that there is no conflict of interest.

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Abbreviations

BMI: Body mass index
DSM-IV: Diagnostic and statistical manual of mental disorders, fourth edition
HADS: Hospital anxiety and depression scale
HbA1c: Glycated hemoglobin
PHQ-9: Patient health questionnaire-9
SDS: Standard deviation score
STROBE: Strengthening the reporting of observational studies in epidemiology
T1D: Type 1 diabetes mellitus

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