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Diabetes Management and Problems Experienced by Patients with Type 1 Diabetes Mellitus During the COVID-19 Pandemic: A Qualitative Study

Tip 1 Diabetes Mellitus Hastalarının COVID-19 Pandemisi Döneminde Diyabet Yönetimi ve Yaşadığı Sorunlar: Kalitatif Çalışma

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ABSTRACT

Objective: A study was conducted to obtain information about problems in diabetes management experienced by patients with type 1 diabetes mellitus during the coronavirus disease (COVID-19) pandemic.

Materials and Methods: In this qualitative study, in-depth interviews were carried out with 43 patients with type 1 diabetes mellitus (25 women, 18 men) aged 18-34 years who volunteered to participate. Each interview lasted 30 to 35 minutes. The conventional content analysis of data was performed using Graneheim & Lundman method.

Results: The mean age of the participants was 26.05±8.01 years, the mean HbA1c level was 9.57±2.57%, and the duration of diabetes was 8.70±5.22 years. The study revealed 7 problem areas related to the patients' diabetes management during the COVID-19 pandemic: blood glucose control, dietary adherence, insulin dose adjustment, exercising, psychosocial problems, sleep problems, and compliance with COVID-19 preventive measures.

Conclusions: The study's results showed that during the COVID-19 pandemic, patients with type 1 diabetes mellitus experienced difficulties in diabetes management and negatively impacted psychosocially.

Keywords: COVID-19, qualitative research, type 1 diabetes mellitus

ÖZ

Amaç: Çalışma Yeni Koronavirüs Hastalığı (COVID-19) pandemisi sürecinde Tip 1 diyabetlilerin diyabet yönetimi ile ilgili yaşadıkları sorunlar konusunda bilgi edinmek amacıyla yapılmıştır.

Materyal ve Metot: Kalitatif türde olan bu araştırmada tip 1 diyabetli, çalışmaya katılmaya istekli, yaşları 18-34 arasında olan 43 (25 kadın, 18 erkek) hasta ile derinlemesine görüşme yapıldı. Her bir görüşme 30-35 dk. sürdü. Verilerin içerik analizi Graneheim & Lundman yöntemi kullanılarak gerçekleştirilmiştir.

Bulgular: Katılımcıların yaş ortalaması 26,05±8,01 yıl, HbA1c ortalaması %9,57±2,57 diyabet süresi 8,70±5,22 yıldır. Çalışmada COVID-19 pandemisi sürecinde diyabetlilerin diyabet yönetiminde yaşadıkları sorunlar ile ilgili 7 sorun alanı belirlendi. Bunlar; kan şekeri kontrolü, beslenmeye uyum, insülin dozunu ayarlama, egzersiz yapma, psikososyal sorunlar, uyku sorunları ve COVID-19 önlemlerine uyum idi.

Sonuç: Çalışmanın sonuçları Tip 1 diyabetli bireylerin COVID-19 pandemisi sürecinde diyabet yönetimini sağlama konusunda sorun yaşadıklarını ve psikososyal yönden olumsuz etkilendiklerini gösterdi.

Anahtar Kelimeler: Covid-19, kalitatif çalışma, tip 1 diabetes mellitus

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INTRODUCTION

Evidence indicates that COVID-19 is more severe in older adults, patients with chronic diseases such as diabetes, heart, lung, and kidney disease, and immunocompromised patients.[1,2-6] Furthermore, it has been shown that type 1 diabetes (T1DM) mellitus and poor glucose control are associated with a higher risk of contracting infections, especially in patients with high glycated hemoglobin (HbA1c) levels and/or insulin resistance due to impaired immunity.[7,8] Therefore, it is critical to take necessary isolation measures to prevent patients with diabetes from contracting COVID-19, as well as encourage adherence to diet, physical activity, and drug treatment during this period and reduce their fear and anxiety to facilitate diabetes management.

The effectiveness of drug therapy, physical activity, and diet programs in patients with diabetes is evaluated by regular health checks, and the necessary precautions are taken at this stage. These evaluations allow the healthcare team to make the arrangements needed for disease management.[9] During the pandemic, nationwide restrictions were implemented in Türkiye when case numbers increased, as in many countries worldwide. Citizens were instructed to "stay home" and were only allowed to leave the house to meet their basic needs. In addition, many hospital outpatient clinics were closed, and healthcare workers had to treat COVID-19 patients.[10] The Society of Endocrinology and Metabolism of Türkiye has recommended that patients with diabetes postpone their routine follow-up appointments, avoid presenting to health institutions unless there is an emergency, and contact health institutions or physicians and nurses primarily by phone if they think they have a disease-related emergency during the pandemic.[9]

In the management and follow-up of chronic diseases, both telemedicine initiatives and mobile health applications offered by telephone operators have had positive impacts on patient care, education, and treatment.[11]

This study was conducted to obtain information about the problems related to diabetes management faced by people with diabetes during the COVID-19 pandemic.

MATERIALS AND METHODS

Ethics Committee Approval: The study was approved by the Clinical Research Ethics Committee of the Istanbul Health Sciences University Kanuni Sultan Training and Research Hospital (Date: 17.05.2020, decision no: 17). The study was performed according to the Declaration of Helsinki.

Sample and Study Design: This qualitative study was conducted by telephone using a semi-structured interview form during the period of nationwide pandemic restrictions. The sample included 43 patients with T1DM who were between the ages of 18 and 34 years, were registered in the Kanuni Sultan Training and Research Hospital Internal Medicine Outpatient Clinic and Diabetes Education Unit and volunteered to participate in the study.

Data Collection Tools: After obtaining institutional permission, the patients enrolled in the center were contacted by phone and their verbal consent to participate in the study was obtained. Telephone interviews with consenting patients were performed using a semi-structured interview form between May 20 and June 30, 2020. The interview form included the following questions: *Can you tell us about your health concerns at the moment? Do you measure your blood glucose? Has there been a change in your diet, exercise habits and sleep pattern? Has there been a change in your blood glucose results? Have you made any changes in your medication use/ dosage during this period? Are you able to go to the hospital for your diabetes follow-up?, and What are you doing to protect yourself from Covid-19?* As it was not possible to carry out a community-based face-to-face survey during this period, a qualitative telephone interview study was conducted on young adults with T1DM. All interviews were conducted by a diabetes education nurse. The diabetes education nurse is the researcher who knows the patients and is responsible for their follow-up. The nurse received online training regarding the study questions and characteristics. Interviews were held with 3 to 4 patients a day, with each interview lasting 30 to 35 minutes. The interviews were recorded using an audio recorder. Information about the patients' medical history was obtained from their records.

Statistical Analysis: The conventional content analysis of data was performed using Graneheim & Lundman method (Table 1)**.** Each interview was independently transcribed by two researchers and the transcripts were analyzed manually using qualitative content analysis. Each statement was read several times, and the relevant parts were extracted. Each response was evaluated and categorized. Responses with the same meaning and content were grouped for each question. The researchers discussed the analyses, and all identified responses were reviewed, after which a final discussion was held among the team members. As a result, 7 problem areas were identified: blood glucose control, dietary adherence, insulin dose adjustment, exercise, anxiety/fear/anger, sleep problems, and compliance with COVID-19 preventive measures. The distribution of sociodemographic and disease characteristics of the participants was evaluated by means of percentages and means.

Table 1. Graneheim and Lundman's 5-step content analysis approach Graneheim and Lundman's steps.

1. Transcription: Implementing the interviews' texts
2. Meaning units: Reading the interviews to gain a general understanding
3. Abstraction: Determining the meaning of units and initial codes
4. Sorting the codes: Classifying similar initial codes into more comprehensive and general categories
5. Theme formulation: Introducing the categories' main theme

RESULTS

As seen in Table 2, the mean age of the participants with T1DM was 26.05±8.01 years, 58.1% were female and middle class, 69.8% were high school graduates, and 67.4% were single. The mean HbA1c level was 9.57±2.57%, and the duration of diabetes was 8.70±5.22 years.

The study revealed 7 problem areas related to the patients' diabetes management during the COVID-19 pandemic: (1) blood glucose control, (2) dietary adherence, (3) insulin dose adjustment, (4) exercising, (5) psychosocial problems, (6) sleep problems, and (7) compliance with COVID-19 preventive measures (Figure 1).

Table 2. Sociodemographic and disease-related characteristics (n=43).

Sociodemographic Characteristics		**n (%)**
Sex	Female	25 (58.1)
	Male	18 (41.9)
Age (years), mean±SD (range)		26.05±8.01 (18-47)
Fasting blood glucose, (mg/dl), mean±SD (range)		228.81±101.44 (104-584)
HbA1c, (%), mean±SD (range)		9.5±2.5 (6.5-15.8)
BMI, (kg/m^2), mean±SD (range)		23.69±4.31 (16.85-37.18)
Diabetes duration, (years), mean±SD (range)		8.70±5.22 (1-23)
Education level, n (%)	Middle school	13 (30.2)
	High school	30 (69.8)
Marital status, n (%)	Married	14 (32.6)
	Single	29 (67.4)
Occupation, n (%)	Homemaker	7 (16.3)
	Freelance/Self-employed	1 (2.3)
	Government employee	5 (11.6)
	Worker	5 (11.6)
	Student	25 (58.1)
Economic status, n (%)	High	18 (41.9)
	Middle	25 (58.1)

SD: Standard deviation; HbA1c: Glycated hemoglobin; BMI: Body mass index.

Figure 1. Themes related to diabetes management and problems experienced by patients with type 1 diabetes mellitus.

The problems identified in content analysis and the patients' statements are presented below.

Patients are asked to measure and record their preprandial and postprandial glucose levels. However, it was determined that all participants had major problems with blood glucose measurement during the COVID-19 pandemic. These problems included not measuring, having higher-than-expected blood glucose levels, and experiencing frequent episodes of hypoglycemia. Reasons stated for not measuring blood glucose were inability to obtain supplies or forgetting. During the COVID-19 pandemic, it was observed that there were problems with insulin dose adjustment, a practice that the patients have become accustomed to and that raised their self-awareness. It was understood from the patient statements that they took more or less insulin than necessary, and that some doses were skipped. Nearly all the patients reported changes in their usual diet. Problems such as overeating, skipping snacks, loss of appetite, and a change in eating patterns were described. Participants had problems due to being at home all the time and their lives becoming sedentary (Table 3).

Table 3. Problems with blood glucose measurements, adjusting insulin dose, dietary adherence and exercising during the COVID-19 Pandemic.

THEME	QUOTATIONS
Problems with blood glucose measurements	"*I ran out of strips, so I haven't been able to measure my blood sugar for a month. I couldn't get them because I couldn't go out" (female, age 21).* "*My levels are terrible, my blood sugar doesn't fall below 500, the lowest is 400... There are sudden ups and downs, and it's really hard on me" (female, age 30).* *"I am under a lot of stress because of the situation we are in, no matter how careful I am, my blood sugar is very high" (female, age 20).* "*My evening preprandial levels have risen into the 300 to 400s for the last two days" (female, age 18).* "*I've been stuck at home since COVID-19 started. My blood sugar falls to between 50 and 100. I go into hypoglycemia very often" (male, age 23).* "*Every day my blood sugar either falls too much or rises too much. I have this problem a lot these days" (male, age 18).*
Problems adjusting insulin dose	"*I increase the insulin dose according to the food I eat and the results. For example, if it turned out to be 400 and I needed to make 12, I'll make 14... I measure, and my blood sugar is low sometimes and high other times. I think being at home all the time has thrown everything off" (female, age 38).* *"Since I'm always at home, I can't wake up in the morning because I go to sleep late at night, I get up in the afternoon... then I can't do my morning insulin and my insulin hours get mixed up" (male, age 23).*
Problems with dietary adherence	"*I started to not be able to control my eating. I'm eating too much. I know you're not supposed to eat it, but I can't control it and then I throw my candy across the room" (female, age 21).* "*In these three months, I went from 55 kilos to 72 kilos. During this time, when I stay at home, I feel like eating constantly" (male, age 23).* "*My mealtimes have changed a lot; just so the day ends sooner, breakfast time is like 12" (female, age 27).*
Problems with exercising	*"I live an inactive life and am constantly at home, I'm feeling anxious, really, my health is not good" (male, age 38).* *"I am not active at home; to be honest I'm constantly sitting" (male, age 20).* *"I can't say that my health is good right now... I can't exercise" (female, age 21).*

All the participants stated that they had been negatively affected during the pandemic, that they experienced anxiety, that thoughts of their or their relatives' illness or death had an adverse impact on their daily lives, and that they had problems coping with these feelings. It was determined that anxiety, fear, and inability to control their anger were their main psychosocial problems. All the participants said they had sleep-related problems. This included the inability to fall asleep, going to bed late at night, having nightmares, waking up late in the morning and not feeling rested, and losing the feeling of waking up to a new day. Participants reported complying with COVID-19 precautions such as wearing a mask, practising hand hygiene, and following social distancing rules. They also mentioned never going out, not being able to socialize, and education being adversely affected (Table 4).

Table 4. Psychosocial, sleep problems and compliance with COVID-19 measures during the COVID-19 Pandemic.

THEME	QUOTATIONS
Psychosocial problems	*"To be honest, how to put it... I mean, I have to do something, but I can't leave the house, I'm overwhelmed, I'm afraid that I will get infected. I am overwhelmed by everything and worried about not being able to go out and go to my check-ups" (male, age 22).* *"I mean, people inevitably get stressed, they're afraid... After all, no matter how much we're at home, it is not clear where this virus will come from" (female, age 20).* *"I try to manage my blood sugar according to the problem or crisis of that moment… I am much more pessimistic than before, I have no hope anymore" (male, age 25).* *"Being in a bad way psychologically affects my diabetes... I get very aggressive during the day, I get angry at everything and I can't help it" (male, age 21).*
Sleep problems	*"I used to sleep so well, I was going to bed at 10 o'clock, getting up at 6 in the morning, going to school. Now in this quarantine, damn it, I can't get to sleep until 5, I toss and turn" (female, age 20).* *"I can't sleep at night at all. My blood sugar is too high in the morning because I can't sleep" (male, age 23).* *"My sleep pattern is nonexistent in these last months. I am already really afraid of the pandemic. I always have bad dreams, so I could not sleep at all. I am so bad right now, it's really hard" (female, age 36). "I usually sleep around 7:30 in the morning, my sleep schedule is generally messed up, I never sleep at night" (female, age 20).*
Compliance with COVID-19 measures	*"I am always at home during this time, I never go out. There aren't many people coming and going at home. [We put on] our mask, our gloves; when we get groceries, we bring them home and soak them in vinegar water in the packages, then rinse them and put them in the cupboards" (male, age 38).* *"Mask, then visor, then when we come home, we wash our hands and faces. I take necessary precautions" (male, age 32).* *"I try not to go out, I'm always at home. My mother stopped sending me to school as soon as the virus appeared, just in case. After all, we are a young group and our immunity is very low" (female, age 20).* *"I usually don't let anyone in the house because I have diabetes, and I never go out" (male, age 18).*

DISCUSSION AND CONCLUSION

It has been established that diabetes leads to increased risk of severe pneumonia and sepsis secondary to viral infection and is present in approximately 20% of these patients.[12,13] Although there are many uncertainties, understanding the problems people with diabetes face in managing their disease and providing them with the necessary care are among the primary goals. In a UK study reporting 23,804 in -hospital COVID-19 fatalities, 1.5% had T1DM, 32% had type 2 diabetes mellitus, and the risk of in-hospital death was 3.5-fold higher in T1DM and 2.03-fold higher in type 2 diabetes when compared with patients without diabetes.[14] This requires patients with T1DM to monitor their blood glucose, adhere to drug therapy, manage their diet, and exercise regularly to protect their short- and long-term health and quality of life.[15]

Effective self-disease management likely improves glycemic control and thus reduces the risk of diabetes-specific disability and complications.[9] In this study, we determined that patients had difficulty managing their diabetes during the COVID-19 pandemic in terms of diet adherence, performing regular insulin injections, exercising, and measuring blood glucose. In the study by Pal et al.,[16] 90% reported a reduction in physical activity and 72% experienced worsening of glycemic control post-lockdown. This clearly demonstrates that people with diabetes need to be monitored and supported during the pandemic. The high HbA1c levels in the participants included in this study are an important indicator that they had problems managing their diseases before the COVID -19 pandemic as well. An extensive survey conducted in Pakistan demonstrated low knowledge regarding COVID-19 in the general population, highlighting the need for greater awareness of COVID-19 and its health impacts.[17] Establishing a valid relationship between diabetes and COVID-19 is imperative in the treatment of patients. It can be considered an encouraging finding that all participants in this study complied with COVID-19 preventive measures.

As the COVID-19 pandemic has swept the globe, the frightening mortality rates in some countries have contributed to the emergence of many psychological problems, including anxiety, depression, and stress.[18] In this study, all the participants reported frequently experiencing feelings of anxiety, fear, and anger. The inability to cope with these emotions may lead to problems such as anxiety and depres-

sion. The psychological impact of pandemic-induced restrictions can lead to symptoms such as confusion, anger, and post-traumatic stress symptoms.[19,20] In a survey of 1210 people in China during the COVID-19 outbreak, half of respondents rated the psychological impact of the outbreak as moderate to severe, 17% reported moderate to severe depressive symptoms, 29% reported moderate to severe anxiety symptoms, and 8% reported moderate to severe stress levels.[21]

All the participants in this study reported having sleep problems. Lifestyle changes are an important factor affecting circadian rhythm. Disruptions in circadian rhythm affect individuals in both physical and social terms.[22] The bidirectional and time-dependent physiological relationship between sleep and glucose control is of clinical importance for patients with T1DM.[23] The HbA1c values of adults with T1DM who slept less than 6.5 hours were found to be significantly higher than those who slept longer.[24] Our study group reported not being able to fall asleep, going to sleep very late at night, having nightmares, waking up late in the morning and not feeling rested, and losing the feeling of waking up to a new day during the COVID-19 pandemic. These problems may have resulted in poor glycemic control.

In conclusion, the results of this study show that patients with T1DM have problems sustaining disease management during the COVID-19 restrictions and that all patients were negatively affected during his period. The patients mainly reported issues related to diet, blood glucose measurement, insulin dose adjustment, and exercise. In addition, psychosocial effects were a significant issue, and sleep emerged as another critical problem area. The results of this study demonstrate essential reasons why people with diabetes require follow-up and support during the COVID-19 pandemic. There are several limitations in our study. Participants were chosen from a group of volunteers who might share diverse opinions and experiences. Therefore, the outputs of the survey may express something other than the fixed results. Data that were used carry the potential of subjectivity, considering that they were collected through intensely interrogated meetings with participants - which allowed them to share their emotions and personal opinions. The study was conducted on a period during the COVID-19 pandemic. The results may vary at the following stages of the pandemic or under different circumstances. Generally, high HbA1c rates were observed among the participants. This observation might show that the participants' already existing troubles in navigating Diabetes. Therefore, the outputs may not be suited for adaptation to the whole population with Diabetes. Sample with a broader sense, long-term observations in various periods and under different circumstances can help us to understand the difficulties T1DM patients were faced better.

Ethics Committee Approval: The study was approved by the Clinical Research Ethics Committee of the Istanbul Health Sciences University Kanuni Sultan Training and Research Hospital (Date: 17.05.2020, decision no: 17). The study was performed according to the Declaration of Helsinki.

Conflict of Interest: No conflict of interest was declared by the authors.

Author Contributions: Concept – MK, SC; Supervision – MK, AK; Materials –SC, GA; Data Collection and/or Processing –SC, GA; Analysis and/ or Interpretation – MK, SC; Writing – MK, SC.

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