



# Living with Type 1 Diabetes: A Qualitative Study

## Tip 1 Diyabet ile Yaşamak: Nitel Bir Çalışma

 Bakiye PINAR<sup>a</sup>,  Türkan TURAN<sup>b</sup>

<sup>a</sup>Pamukkale University Hospital, Denizli, TURKIYE

<sup>b</sup>Department of Nursing, Division of Pediatric Nursing, Pamukkale University Faculty of Health Sciences, Denizli, TURKIYE

**ABSTRACT Objective:** Type 1 diabetes is an absolute insulin-dependent autoimmune disease. It is generally seen in children and adolescents and its prevalence is increasing day by day. The management of a chronic disease during adolescence may affect the individual's biological, psychological and socialization processes. Purpose: This study was conducted to determine how Type 1 diabetes affected the lives of adolescents. **Matreial and Methods:** This qualitative study is of a phenomenological type. The study covered a total of 19 adolescents (14 girls and 5 boys) in 12 to 18 age group at a Pamukkale university hospital, who were followed up with the diagnosis of type 1 diabetes. In the study, the data were collected by using the semi-structured interview form and through the in-depth interview method. Interviews were recorded and ranged from a minimum of 15 minutes to a maximum of 45 minutes. The data obtained were evaluated using the content analysis method. **Results:** Adolescents with type 1 diabetes were affected in terms of experience, emotion and perception. **Conclusion:** As a result of this study, it has been found that type 1 diabetes affects adolescents' lives in many ways. In the follow-up of the disease, healthcare professionals should be aware of the factors that negatively affect the quality of life of adolescents by reducing their compliance with the disease and treatment, and should include the elimination of these factors or keeping them under control in their care.

**Keywords:** Adolescents; qualitative study; Type 1 diabetes mellitus

**ÖZET Amaç:** Tip 1 diyabet mutlak insüline bağlı otoimmün bir hastalıktır. Genellikle çocuklarda ve ergenlerde görülmekte olup her geçen gün yaygınlığı da artmaktadır. Adölesan döneminde kronik bir hastalığın yönetimi bireyin biyolojik, psikolojik aynı zamanda sosyalleşme süreçlerini de etkileyebilir. Amaç: Bu çalışma; tip 1 diyabetin adölesanların yaşamlarını nasıl etkilediğini belirlemek amacıyla yapılmıştır. **Gereç ve Yöntemler:** Araştırma fenomenolojik tipte niteliksel olarak yapılmıştır. Pamukkale üniversite hastanesinde, tip 1 diyabet tanısı ile takibi yapılan 12-18 yaş grubu, 14 kız ve 5 erkek olmak üzere 19 adölesanı kapsamaktadır. Çalışmada veriler yarı-yapılandırılmış görüşme formu kullanılarak derinlemesine görüşme yöntemi ile toplanmıştır. Görüşmeler kayıt altına alınmıştır, en az 15 dakika ile en fazla 45 dakika arasında değişmiştir. Elde edilen veriler içerik analizi yöntemiyle değerlendirilmiştir. **Bulgular:** Tip 1 diyabet ile yaşayan adölesanlar deneyim,duygu ve algı yönünden etkilenmişlerdir. **Sonuç:** Bu çalışmanın sonucunda tip 1 diyabet hastalığının adölesanların yaşamlarını birçok yönden etkilediği bulunmuştur. Hastalığın takibinde sağlık çalışanları adölesanların hastalığa ve tedaviye uyumlarını azaltarak yaşam kalitelerini olumsuz etkileyen faktörlerin farkında olmalı ve bakımında bu faktörlerin ortadan kaldırılması veya denetim altında tutulması konusuna yer vermelidir.

**Anahtar Kelimeler:** Adölesan; nitel araştırma; Tip 1 diabetes mellitus

Diabetes mellitus is a metabolism disease that occurs with hyperglycaemia as a result of insufficient insulin secretion of the pancreas or impaired insulin use. Chronic hyperglycaemia causes long-term dam-

ages to the body and life-threatening complications in tissues and organs. The aetiology of which is not fully understood, Type 1 diabetes mellitus is a type of diabetes which occurs with absolute insulin defi-

**Correspondence:** Bakiye PINAR  
Pamukkale University Hospital, Denizli, TURKIYE/TÜRKİYE  
**E-mail:** bakiye.0909@gmail.com



Peer review under responsibility of Türkiye Klinikleri Journal of Pediatrics.

**Received:** 25 Nov 2020

**Received in revised form:** 24 Dec 2021

**Accepted:** 11 Jan 2022

**Available online:** 13 Jan 2022

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ciency due to the destruction of beta cells of the pancreas and is common in children and adolescents.<sup>1</sup> The prevalence of Type 1 diabetes patients under the age of 20 in Turkey was 0.75/1,000 and the incidence was 10.8/100,000. Turkey accounts for approximately 3% of Type 1 diabetes mellitus cases worldwide, it has been reported that the prevalence of girls diagnosed with Type 1 diabetes is higher than boys and they are mostly diagnosed between the ages of 10-14.<sup>2</sup>

Adolescence is the period that individuals undergo biological, cognitive, psychosocial and sexual changes during the period of transition from childhood to adulthood and develop abstract thinking to become an independent individual.<sup>3</sup> Occurrence of diabetes during this period is quite a difficult condition for adolescents. A chronic disease such as diabetes can affect the development of adolescents.<sup>4</sup>

Chronic diseases are among the most important conditions that affect the quality of life of individuals. Factors such as limitation in daily activities of diabetic adolescents, disease symptoms, insulin injection, diet, exercise, blood glucose monitoring cause deterioration in the quality of life of adolescents, and problems experienced in the treatment and management of the disease (frequent polyclinic control, repeated hospitalizations, complications) negatively affects the physical, cognitive, psychological state, school and social life, friendships, academic success and psychological resilience of the adolescent.<sup>5-8</sup>

Type 1 diabetes affects adolescents' lives physically, psychologically and socially. It is important for adolescent health that health care professionals are aware how Type 1 diabetes affects adolescents' lives and the difficulties they experience.

## MATERIAL AND METHODS

### STUDY TYPE

This qualitative study of phenomenological type was conducted to determine how Type 1 diabetes affect the lives of adolescents. Adolescents between 12-18 years old who were diagnosed with Type 1 diabetes at least 6 months ago and who were physically and mentally

sufficient to express their feelings were included in the study. Interviews were ended with 19 adolescents (14 females and 5 males) with data saturation.

### LOCATION AND TIME OF STUDY

The study was carried out in the Paediatrics Clinic of Pamukkale University Hospital. The study data were collected between 01.04.2018 and 31.08.2018.

### COLLECTION OF DATA

The data of the study were collected through in-depth interviews. The study used a semi-structured interview form. The questions in the interview form were asked to each adolescent in the same order and format. Interviews with adolescents were made face-to-face by the interviewer. The data collection process continued until similar concepts were obtained. Before starting the interviews, the clinic was visited first, the healthcare team, adolescents and parents were interviewed to schedule and determine the time and location of the study. The adolescents who accepted the interview were explained that data to be acquired from the study would be used for the study anonymously, and were asked to sign a consent form voluntarily. The interviews were held and recorded in a quiet environment in a seminar room. The interviews were conducted with a single researcher to ensure standardization. The duration of the interviews ranged from 15 minutes to 45 minutes.

### DATA ANALYSIS

The data obtained from the interviews were evaluated using the content analysis method. Content analysis is a technique that is used to analyse the content of sentences by examining words, themes, idioms in one or more texts.<sup>8</sup> The interviews recorded were analysed upon completion and then, written as raw data using a computer. The raw data were examined by three (3) researchers separately, and appropriate themes and codes were created accordingly. The codes were then reorganized under themes and all the data were interpreted and written in a report.

### STUDY ETHICS

Ethics committee approval was obtained from Pamukkale University Non-interventional Clinical Researches Ethics Committee (60116787-020/2690,

11.01.2018). The patient and parents who agreed to participate in the study were informed about the study, and verbal and written consent was obtained from the parents and children who agreed. In addition, this study was carried out in accordance with the Helsinki Declaration principles.

## RESULTS

Introductory characteristics familial characteristics of the interviewed adolescents and findings regarding life experiences, emotions and perceptions of are given (Table 1, Table 2, Table 3).

### FINDINGS REGARDING LIFE EXPERIENCES, EMOTIONS AND PERCEPTIONS OF ADOLESCENTS WITH TYPE 1 DIABETES MELLITUS

As a result of the analysis obtained from the adolescents interviewed, three (3) main themes were identified: experience, feeling and perception. In the first main theme, adolescents with Type 1 diabetes reported their experiences. In the second main theme, adolescents explained how it felt to have diabetes. The third main theme was about how adolescents perceived themselves as individuals with diabetes.

**TABLE 1:** Descriptive characteristics of adolescents.

Features	Number of patients (n=19)	%
Average age=15.5		
Gender		
Girl	14	73.7
Boy	5	26.3
Educational status		
Middle school	4	21.1
High school	15	78.9
Duration of diabetes		
6 months-1 year	6	31.6
1year-5years	8	42.1
More than 5 years	5	26.3
Presence of diabetes in the family		
Yes	7	36.8
No	12	63.2
Family structure		
Core	15	78.9
Broken	4	21.1
Where he lives		
Rural	3	15.8
Urban	16	84.2

**TABLE 2:** Familial characteristics of adolescents.

Characteristics	Number of patients (n=19)	%
Father education		
Primary school	3	15.8
Middle school	15	78.9
High school	1	5.3
Father occupation		
Employee	12	63.2
Farmer	1	5.3
Self-employment	6	31.6
Mother education		
Literate	1	2.3
Primary school	8	42.1
Middle school	10	52.6
Mother occupation		
Employee	10	52.6
Farmer	1	5.3
Housewife	8	42.1
Sibling presence		
2	14	73.7
3	5	26.3

**TABLE 3:** Themes and subthemes.

Theme	Subtheme
Experience	Difficulties in adaptation to diabetes
	Social restrictions
Feeling	Fear of social stigma
	Feelings experienced during control visits
	Feelings experienced at the time of diagnosis
Perception	Negative perceptions
	Positive perceptions

### THEME 1: Experience

It was found out as a result of the study that the theme “experience” had 2 sub-themes, “difficulties” and “social restrictions” in adaptation to diabetes.

#### - Difficulties in Adaptation to Diabetes

Adolescents experienced difficulties in adaptation to diabetes due to conditions such as diabetes being a chronic disease, restrictions in nutrition, insulin calculations, desire to be independent and diabetes being a disease that requires attention due to possible complications.

**- Social Restrictions**

In our study, adolescents diagnosed with Type 1 diabetes experienced social isolation as a result of difficulties in school environment, their inability to participate in social activities and negative reactions from their circles because they were diabetic. Female adolescents were more restricted socially due to gender difference. In our study, negative reactions from their circles caused adolescents to be upset.

would be excluded by others because they had diabetes, and therefore, hid their disease, felt different from their peers due to diabetes, and felt embarrassed when administering their insulin injection in crowd.

**- Feelings Experienced During Control Visits**

In our study, adolescents experienced stress from the reactions of healthcare professionals and the

THEME 1 Patient opinions	Subthemes	Theme
<p><i>"Many things change after diabetes; for example, I cannot eat everything, there are restrictions which I cannot always pay attention."</i> (Female, age 17)</p> <p><i>"I was very scared when I was told that I would lose my eyes and my kidneys would not work when I did not follow my treatment. I remember them as soon as my blood sugar rises."</i> (Female, age 14)</p> <p><i>"When I come home from school, my mother immediately asks me if I tested my blood sugar. In the evenings, she keeps saying and asking administer your injection, sometimes I get angry, I can do something on my own now, right?"</i> (Female, age 13)</p> <p><i>"I am going to school. In the lesson, you always need go to the toilet and eventually, you are interrupted constantly. For example, I was getting worse in the lesson, and then friends in the class used to say I was pretending, I was upset when I heard them. Why would I pretend!"</i> (Female, age 16)</p> <p><i>"Sometimes, I feel sorry for my father, he is very afraid that my blood sugar will drop and keeps asking about my blood sugar, feel like a little kid too."</i> (Female, age 16)</p>	<p>Difficulties in adaptation to diabetes</p>	<p>Experience</p>
<p><i>"Our neighbours told my mother that I would not recover from this disease and would not be able to work in the future."</i> (Male, age 16).</p> <p><i>"I will never be on the same level with people. I will always need to devote my time to checks, hospital and treatment."</i> (Female, age 16).</p> <p><i>"... My parents do not want to send me out alone, they say you are a girl and your blood sugar may drop, so go with your sister." "I cannot go out alone."</i> (Female, age 16)</p> <p><i>"I was very upset when I was told that I had diabetes, I thought I could not get married in the future, I would not have a child."</i> (Female, age 16)</p>	<p>Social restrictions</p>	

**THEME 2: Feelings**

As a result of the study, three sub-themes were identified under the theme of feeling, being the fear of social stigma, feelings experienced during control visits and feelings experienced at the time of diagnosis.

**- Fear of Social Stigma**

It was found out that some adolescents tended to deliberately refuse treatment as they thought that they

idea of hospitalization when they came to the hospital because they could not control their diabetes.

**- Feelings Experienced at the Time of Diagnosis**

In our study, adolescents experienced sadness, fear, shock and denial when they were first told that they had diabetes. Adolescents who were diagnosed with diabetes at a young age stated that they became aware of the disease "diabetes" when they reached school age.

THEME 2		
Patient opinions	Subthemes	Theme
<p>"I was so scared that my friends would exclude me because I had diabetes, I thought they would not talk to me." (Female, age 17)</p> <p>"When I was administering my injection at school, my friend said it smelled so bad, and I was very embarrassed at that moment and I did not want to administer my injection, which affected me badly." (Female, age 16)</p> <p>"I am not like my friends... They eat, drink, travel as they want, but I have to pay attention to everything and have to prick my finger constantly." (Female, age 16)</p> <p>"I did not tell all my friends. I just told a close friend of mine because I thought others would make fun of me." (Female, age 16)</p> <p>"I was embarrassed when I was administering my insulin injection in the class because everyone was starting to look at me." (Male, age 14)</p>	Fear of social stigma	Feelings
<p>"It is a very bad feeling and you want to go home. Continuous controls are boring. I am very scared to be hospitalized again when my blood sugar level is high." (Female, age 14)</p> <p>"I am very afraid that I will be hospitalized when my blood sugar is high." (Male, age 14)</p>	Feelings experienced during control visits	
<p>"I was very upset. It made me very sad to have a disease that would never get over in my life." (Female, age 16)</p> <p>"I did not feel anything, I did not know how to react, I was shocked, I can never forget that moment." (Female, age 16)</p>	Feelings experienced at the time of diagnosis	

### THEME 3: Perceptions

In our study, two (2) sub-themes of perceptions were determined, negative and positive perceptions.

#### - Negative Perceptions

Adolescents reported that they had negative perceptions generally because they did not feel free due to the limitations caused by diabetes.

#### - Positive Perceptions

In our study, adolescents perceived themselves positively because they ate healthier than others.

## DISCUSSION

### THEME 1: EXPERIENCES

The development of a chronic disease in the adolescent period causes changes in lifestyle, affects social relationships and gives rise to concerns about the complications of the disease. An adolescent with diabetes said that the most difficult aspect of the disease was that a strict routine should be followed to manage it.<sup>9</sup> Adolescents have difficulties in maintaining metabolic control and adapting to diet, thus negatively affecting their self-esteem.<sup>10-14</sup>

THEME 3		
Patient opinions	Subthemes	Theme
<p>"It is really bad. I will never be on the same level with people. I will always need to devote my time to checks, hospital and treatment, and this feels very bad." (Female, age 14)</p> <p>"You are not like other people, you are not free like them and you cannot do whatever you want, after all your diabetes bring you obstacles." (Male, age 14)</p>	Negative perceptions	Perceptions
<p>"I perceive it positively because to me, being a diabetes patient means eating healthy, we eat much healthier than other people." (Female, age 17)</p> <p>"I know the value of the little things in my life after I have diabetes and I perceive myself positively as it changed my perspective." (Female, age 14)</p>	Positive perceptions	

Studies have shown that children with Type 1 diabetes have lower self-esteem than healthy children.<sup>15</sup> It has been found in studies that adolescents with low self-esteem do not comply with diet and their interpersonal relationships cannot be carried out appropriately.<sup>16,17</sup>

In our study, adolescents stated that they felt their independence was restricted as a result of the constant intervention of families about the treatment of diabetes and felt uncomfortable that they were treated like a small child. In the study, it was found out that parents prevented adolescents with diabetes from making their own decisions independently and that their protective and oppressive attitudes caused stress on adolescents.<sup>18</sup> Overprotective parents take full responsibility for the disease. This prevents the independence of the adolescent and leads to the adolescent-parent conflict.<sup>19</sup> It also prevents the adolescent from controlling himself/herself and developing his/her self-esteem.<sup>10</sup>

In the presence of a chronic disease, adolescents' perceptions about their body image are negatively affected due to adverse changes in their physical appearance.<sup>19</sup> In particular, female adolescents reported that injection sites affected their body image adversely and that they were embarrassed by their people around them.<sup>20</sup> Female adolescents who participated in our study stated that they were concerned about the scar left on the injection sites.

The problems that most female adolescents with diabetes worry about are marriage and pregnancy. They had the fear of explaining to their fiancé and their families that they had diabetes and the fact that diabetes would affect their future plans caused them to worry.<sup>20-22</sup> It is thought that adolescents with Type 1 diabetes experience social stigma due to social values and cultural influence.

## THEME 2: FEELING

In our study, adolescents have the fear stated that experienced of exclusion. Adolescents who received peer support stated that they felt better. Causes such as problems in peer relationships, feeling different from their peers, not being included in the peer group can further increase stress, depression and social anxiety in adolescents.<sup>23-25</sup> When the studies were exam-

ined, it was determined that positive peer support protects adolescents against social anxiety, while negative peer support contributes to the social anxiety of adolescents.<sup>26,27</sup>

Adolescents who participated in our study showed a tendency to hide their disease from people around them. Young people with Type 1 diabetes were stressed not knowing what and when to tell people around them about diabetes and tended to hide it from others.<sup>28-30</sup> Adolescents with diabetes stated that the prejudice of, and rejection by other people caused them to feel insecure, difficulties in developing relationships with their peers and others and that they felt fear and shame as an individual with diabetes.<sup>31,32</sup>

In our study, adolescents experienced shock, denial and discredit when they were told that they were diagnosed with diabetes for the first time. It was reported that people who went to the hospital for any other problems and figured out that they were unexpectedly diagnosed with diabetes experienced shock, fear, anger and freezing.<sup>33</sup>

## THEME 3: PERCEPTIONS

In our study, adolescents' not being like their friends, not being able to do whatever they wanted, devoting most of their time to treatment caused them to perceive themselves badly. Adolescents experienced the psychological stress of having diabetes. They stated that they were different from their friends, could not do what they wanted like their friends and were busy with the treatment of diabetes for insulin injection and blood glucose test.<sup>29,34</sup>

Since they had been diagnosed with diabetes, these adolescents had learned to know their own bodies. They had gained knowledge about healthy food and the importance of regular exercise and described this knowledge as positive. In the study, adolescents stated that they ate healthy, did exercises regularly, which as a result, helped them feel better, and some adolescents stated that they were proud to have more knowledge about diabetes than their friends.<sup>9,33</sup>

## LIMITATIONS OF THE STUDY

The results of the study can be generalized only to the adolescents interviewed due to the method. Only



volunteer adolescents participated in the study. Another limitation is that this study has been carried out only at a university hospital and within a certain time period.

## CONCLUSION

Adolescents have revealed that living with Type 1 diabetes has different effects on their experiences, feelings and perceptions. Results from the research,

Adolescents stated that it is difficult to live with Type 1 diabetes.

In the study, it was determined that adolescents face obstacles in participating in social activities due to diabetes.

The oppressive attitudes of families towards the treatment of diabetes cause adolescents to experience stress.

Adolescents fear and worry about possible complications of diabetes.

Adolescent girls participating in the study think that diabetes will prevent them from getting married and having children in the future.

Adolescents tend to hide their illnesses from the environment for fear of being excluded. Adolescents with Type 1 diabetes see themselves as different from their peers and want to live like them.

In line with the results obtained from the research it is recommended;

To enable health professionals to help adolescents express their feelings by encouraging them to express the challenges of living with Type 1 diabetes.

To conduct research to determine the level of knowledge of the society about Type 1 diabetes with the thought of increasing the social cohesion of adolescents,

To evaluate the factors affecting the quality of life of adolescents with Type 1 diabetes and to conduct studies on which strategies are used to cope with a chronic disease.

## Source of Finance

*This study was supported by Scientific Research Coordination Unit of Pamukkale University under the project number 2018S ABE008.*

## Conflict of Interest

*No conflicts of interest between the authors and / or family members of the scientific and medical committee members or members of the potential conflicts of interest, counseling, expertise, working conditions, share holding and similar situations in any firm.*

## Authorship Contributions

**Idea/Concept:** Bakiye Pınar, Türkan Turan; **Design:** Bakiye Pınar, Türkan Turan; **Control/Supervision:** Türkan Turan; **Data Collection and/or Processing:** Bakiye Pınar; **Analysis and/or Interpretation:** Bakiye Pınar, Türkan Turan; **Literature Review:** Bakiye Pınar; **Writing the Article:** Bakiye Pınar, Türkan Turan; **Critical Review:** Türkan Turan; **References and Fundings:** Bap within the scope of the project.

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