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# Factors affecting nonadherence to treatment among type 2 diabetic patients with limited health literacy: Perspectives of patients, their families, and healthcare providers

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## Abstract:

**BACKGROUND:** Treatment adherence is one of the behaviors associated with type 2 diabetes that predicts whether it will be successfully treated or develop complications and become uncontrolled. This study aimed to determine factors affecting nonadherence to treatment among diabetic patients with limited health literacy from the perspectives of patients, their families, and healthcare providers.

**MATERIALS AND METHODS:** This qualitative study with a content analysis approach was conducted on 84 eligible type 2 diabetes patients with limited health literacy and poor adherence to treatment, as well as their families and healthcare providers using a purposive sampling method, in Kerman city in 2021. Interviews were conducted using a semistructured interview guide with a broad, open-ended question to provide a general history of the disease separately. The interviewer asked participants to identify the perceived barriers to treatment nonadherence. Each interview lasted 45–60 min. MAXQDA version 20 and inductive content analysis were used to code and analyze extracted data.

**RESULTS:** Four major themes emerged from the patients' perspectives as "financial problems," "individual factors," "problems related to medication availability," and "healthcare providers' poor practices." Two major themes were classified from the perspective of patients' families as "financial problems" and "Individual factors," and four major themes were identified from the viewpoint of healthcare providers including "financial problems," "individual factors," "scarcity and medication availability," and "poor practice of the healthcare provider." These mentioned barriers were confirmed regarding treatment nonadherence among study participants.

**CONCLUSION:** Study findings revealed different factors of treatment nonadherence among diabetic patients with limited health literacy. Therefore, these factors should be considered in tailoring promotive educational and supportive interventions. Considering the importance of adherence to treatment patients, planning empowerment family-based interventions focusing on health literacy improvement seems necessary.

## Keywords:

Family, health literacy, health personnel, nonadherence to treatment, qualitative research, type 2 diabetes

## Introduction

According to a report by the World Health Organization (WHO), about

422 million people the world over suffer from diabetes mellitus (DM), with Eastern Mediterranean countries accounting for the

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highest prevalence (43 million people). DM is among the 10 highest lethal diseases worldwide and caused 1.6 million deaths in 2016.<sup>[1]</sup>

Treatment adherence as a chronic disease-related behavior predicts treatment success and reduces disease complications and its severity.<sup>[2]</sup> Nonadherence to treatment among patients with chronic diseases can result in adverse consequences including disease progression, hospitalization, mortality, and morbidity.<sup>[3]</sup> Treatment adherence among patients with diabetes can affect treatment outcomes, although treatment adherence among patients with diabetes is quite poor.<sup>[4]</sup> However, diabetes complications can be avoided or delayed as several studies have reported.<sup>[5,6]</sup> In recent years, many health planners and policymakers have implemented various programs to encourage patients to adhere to treatment worldwide.<sup>[5]</sup> Treatment nonadherence among patients with type 2 diabetes is associated with frequent hospitalizations, high tangible and nontangible treatment costs, and a high number of physician visits. The mortality rate among patients who do not adhere to their treatments is twice as high as other patients.<sup>[7]</sup>

The WHO categorizes the various factors influencing treatment adherence into five categories including socioeconomics, healthcare team and service delivery system, disease, treatment, and patient-related factors. Although some of these factors are unmodifiable, patient-related factors can be altered through training and raising patients' awareness and knowledge.<sup>[8]</sup> However, modification in awareness and knowledge does not always result in a change in attitude, and a change in attitude does not always result in a behavior change because the environment may not allow the individual to behave in a certain way.<sup>[9]</sup> Several studies note poor treatment adherence among adults with type 2 diabetes, leading to an increase in disease-related problems and complications.<sup>[10,11]</sup> Guenette *et al.* (2016)<sup>[12]</sup> found that 38% of people with type 2 diabetes did not adhere to treatment during the first year of the disease.

Another important barrier to treatment adherence among patients with diabetes is a lack of health literacy.<sup>[12,13]</sup> Health literacy refers to a person's ability to obtain, interpret, and comprehend basic information about health services that does not necessarily stem from years of study or general reading ability. Health literacy consists of a set of reading, listening, analysis, and decision-making skills, as well as the ability to apply these skills in health situations.<sup>[14]</sup>

People with low health literacy do not understand the oral and written information provided by physicians, nurses, and insurers; they are unable to follow necessary procedures/instructions such as medication regimens

and frequent health services use in health systems. Their knowledge is limited about medical conditions, and they use fewer available preventive services.<sup>[15]</sup> Adherence to treatment, on the other hand, is a key factor in improving the outcomes and problems of patients with diabetes.<sup>[16-18]</sup> In order to cope daily living barriers of diabetes, it is necessary to design appropriate promotive family-based interventions using health promotion theories/models to improve adherence to treatment. There are limited qualitative studies in different countries investigating these factors from the perspective of patients, their families, and healthcare providers.<sup>[19]</sup> However, based on our knowledge, no study was found that explored the experiences of these patients with limited health literacy and their families and health care providers. Exploring the experiences and perspectives of these groups in different contexts and cultures can help design educational programs and interventions suitable for each context. So this qualitative study aimed to identify factors affecting nonadherence to treatment in type 2 diabetes patients with limited health literacy from the perspectives of patients, families, and healthcare providers in Kerman city.

## Materials and Methods

### Study design and setting

This qualitative study with a content analysis approach was conducted on patients, their families, and healthcare providers. The study's settings were the diabetes clinics of Bahonar, Shafa, and Erfan Salamat hospitals in Kerman city.

### Study participants and sampling

Eligible participants were selected using purposeful sampling. In qualitative studies, the sample size was unknown from the beginning, and sampling was terminated when data was saturated.<sup>[3]</sup> In this study, data gathering lasted from May to August 2021 and continued until the data was saturated. The samples in three groups were selected by the purposive sampling method. Finally, the study participants included 26 patients, 39 patients' families, and 19 healthcare providers.

### Data collection tool and technique

Questionnaires on treatment adherence, health literacy, and demographic characteristics were completed for patients referred to the diabetes clinics to select eligible study participants.

The Functional, Communicative, and Critical Health Literacy questionnaire is related to the level of health literacy of people with diabetes, which was validated in Reisi *et al.*<sup>[20]</sup> study. The internal consistency of the questionnaire was obtained with Cronbach's alpha of 0.82. Convergent validity has been investigated using the

S-TOFHILA tool, which has obtained a correlation of 0.45. The questionnaire of treatment compliance is used as a monitoring tool in accordance with the culture of Iranian society, in different stages of treatment implementation in the hospital and in research, and Cronbach's alpha was reported as 0.921 in the validation study, which shows a high reliability and internal validity of this questionnaire. Also, to check the reliability, the important index of interclass correlation coefficient was used, which was obtained for the entire questionnaire as 0.921 with a confidence interval (0.9–0.94).<sup>[21]</sup>

Based on a preliminary assessment to find eligible study participants, patients with low scores in the health literacy questionnaire and treatment compliance questionnaire were identified as having limited health literacy and poor treatment adherence, so they were invited to participate in this qualitative study. A skilled interviewer completed a demographic characteristic for illiterate participants. Age over 30 years, limited health literacy, poor adherence to treatment, diabetes diagnosis of more than six months at least, willingness to participate in the study, and no confirmed psychological problems were considered as inclusion criteria. Pregnant women with gestational diabetes, type 1 diabetes, and underlying diseases unrelated to type 2 diabetes (such as cancer and autoimmune disease, etc.) were excluded from the study. In addition, families and healthcare providers were interviewed separately to investigate the factors affecting poor adherence to treatment among patients. Sons, daughters, siblings, friends, and neighbors of the assessed diabetic patients were included in this study. Health professionals including nurse, psychologist, nutritionist, center manager, and physician were interviewed.

The semistructured interview was the primary method of data collection in this study. Patients, families, and healthcare providers were all interviewed separately to get their perspectives on why patients do not adhere to their treatments. Virtual interviews were conducted in groups of four to five people. These WhatsApp groups (<https://chat.whatsapp.com/KOf6TOLdUg41gUQllylo6F>) were created for patients with type 2 diabetes, their families, and healthcare providers. Therefore, the interviewee could freely describe their own experiences without fear of data disclosure. The interview was conducted with a broad, open-ended question to allow patients, their families, and healthcare providers to describe the illness. In the patient group, sample questions were “How long have you had type 2 diabetes?” and “How long have you been receiving treatment?” Questions as “Do you live with or apart from the patient?” “What is your relationship with the patient?” and “what is your role in the life of the patient?” were asked in the patient's family group. Questions like “How long have

you been caring for the patient?” and “How much do you know about your patient's condition?” were asked in the healthcare provider group. The researcher then asked other questions to all three groups to determine the barriers to treatment nonadherence. Interviews were recorded, transcribed verbatim with the consent of the participants, and analyzed immediately and up to 24 h later. The interviews lasted between 45 and 60 min.

To ensure that the data are acceptable and the study accurately reflects the participants' experiences, the best data collection method and sufficient data, as well as the appropriate and accurate meaning unit, data coverage in categories and themes, judgments about internal similarities and differences between categories, and participants' involvement in confirming the findings, were considered.<sup>[22]</sup> As a result, the researcher's long-term engagement and allocation of sufficient time for data collection were considered. Additionally, the researcher developed a friendly and respectful relationship with the participants, particularly when conducting interviews, listened to people without passing judgment, and combined interview and note-taking. At the end of each interview, the researcher read the results summary aloud to get participants' confirmation regarding their experiences. It is worth noting that the researcher benefited from the professors' experiences and perspectives.

To ensure data reliability over time and under varying conditions, the codes were reread and compared to the original codes a few days after the interviews were transcribed and the initial coding was completed. The data's reliability and consistency were confirmed in the case of comparable results.

Inductive content analysis was used to determine the presence of specific words and concepts in the texts, as well as to reduce, structure, and organize the data. The inductive content analysis begins with the research question and purpose, avoids predefined categories, and allows for the emergence of categories and their names from the data.<sup>[4]</sup> The audio files of the interviews were immediately drafted, and then the manifest and latent contents were obtained through several careful readings and note-taking. MAXQDA version 20 was used to enter, code, and categorize data. By identifying the key points, we were able to categorize, summarize, and analyze the various viewpoints on the subjects. The process of data analysis was done according to the steps proposed by Graneheim and Lundman.<sup>[23]</sup>

### Ethical consideration

This study was approved by the research ethics committee of Tehran University of Medical Sciences (ethical code number: IR.TUMS.SPH.REC.1399.250). First of all,

the study aim was explained to the participants, and then informed written consent was obtained from eligible individuals. All participants were assured that their information would remain confidential, their participation in the study was voluntary, and that they could withdraw from the study at any time. Participants could contact the researcher if they had any suggestions, criticisms, or information about any problems.

### Results

The mean age of participants in the group of patients with diabetes was 65.38 ± 12.56 years old. The majority of patients were female, married, illiterate/received an elementary education; they were also housewives who lacked sufficient income and were covered by social security. Participants in the patient’s family group had a mean age of 37.44 ± 8.43 years old. They were mostly married, stay-at-home moms, with a diploma. Additionally, the majority of individuals had low incomes, and the majority of them were the sons of patients. The mean age of healthcare providers was 37.58 ± 8.73 years old. The majority of participants were female, married, and nurses with a bachelor’s degree [Table 1].

Patients considered the following factors as barriers to treatment adherence: “financial problems” with a subcategory of undergoing a course of treatment, “Individual factors” with subcategories of incomplete information and misconceptions, concerns and emotional and mental problems, physical problems, illness of other family members, lack of attention and support of the family, loneliness and forgetfulness, “problems related to medication availability” with subcategories of problems related to insulin therapy, multiple medications, and “poor practice of healthcare providers” with subcategories of physician–patient and patient–nurse relationships [Table 2]. Patients’ families mentioned the following factors as barriers to treatment adherence: “financial problems” with the subcategory of undergoing a course of treatment and “individual factors” with the subcategories of interference of personal preferences with treatment recommendations, feelings of family frustration and indifference, individual dependencies, loneliness, inattention, and forgetfulness [Table 3]. The healthcare providers considered the following factors as barriers to treatment adherence: “financial problems” with subcategories of preparing food and undergoing a course of treatment, “individual factors” with subcategories of insufficient information, misconceptions, complications of illness, and home and family environment, “scarcity and problems of medication availability” with the subcategory of problems related to insulin, and “poor practice of the healthcare providers” with the subcategory of the

**Table 1: Demographic characteristics of patients with type 2 diabetes, their families, and healthcare providers**

Patients with type 2 diabetes (n=26)		
Variable	Mean	SD
Age	65.38	12.56
Duration of diabetes (year)	15.00	5.94
Families of patients with type 2 diabetes (n=39)		
Variable	Frequency	Percent
Sex		
Female	20	76.9
Male	6	23.1
Education		
Uneducated	10	38.5
Elementary	10	38.5
Middle school	1	3.8
Diploma	5	19.2
Job		
Housewife	20	76.9
Retired	3	11
Self-employed	3	11
Type of medicine used		
Oral medicine	4	15.4
Injectable medicine	8	30.8
Oral and injectable medicine	14	53.8
Families of patients with type 2 diabetes (n=39)		
Age	37.44	8.43
Sex		
Female	22	56.4
Male	17	43.6
Marital status		
Married	21	53.8
Single	18	46.2
Education		
Uneducated	2	5.1
Elementary	2	5.1
Middle school	4	10.3
Diploma	19	48.7
Associate degree	5	12.8
Bachelor’s degree and higher	7	17.9
Job		
Housewife	13	34.2
Employed	5	13.2
Worker	8	21.1
Self-employed	4	10.5
Unemployed	8	21.1
Income		
Poor	18	47.4
Moderate	15	39.5
Good	5	13.2
Relationship with patient		
Son	13	34.2
Daughter	10	26.3
Brother	3	7.9
Sister	8	21.1
Friend	2	5.3
Neighbor	2	5.3

Contd...

**Table 1: Contd...**

Healthcare providers (n=19)		
Age	37.58	8.73
Sex		
Female	16	84.2
Male	3	15.8
Marital status		
Married	18	94.7
Single	1	5.3
Education		
Bachelor	14	73.7
Master	1	5.3
PhD	4	21.1
Job		
Nurse	6	31.6
Psychologist	2	10.5
Nutritionist	3	15.8
Staff	4	21.1
Physician	4	21.1

physician–patient relationship [Table 4]. Participants also had limited health literacy in relation to illness and health behaviors, which affected the process of adherence to treatment.

### Financial problems

All three groups of patients, their families, and healthcare providers mentioned financial problems as a major barrier to treatment adherence. Patients, who were unable to pay for their treatment, received incomplete care. Financial problems, such as not being able to provide nutrition regimen a special diet, not being able to afford medical procedures, and substituting cheaper medications for those prescribed by physician, all contributed to treatment nonadherence.

**Preparing food:** One of the barriers to treatment nonadherence was the patient’s inability to provide food recommended by physicians.

*“Patients generally do not follow nutritionist’s advice because it is contrary to their lifestyle. Recommendations should be tailored to the patients’ specific circumstances.” (Participant No. 3, a nurse).*

**Undergoing a treatment course:** Patients with diabetes cannot afford disease-related treatment.

*“Because of the high cost of the glucometer strip, patients are unable to maintain proper blood sugar levels, leading to ineffective treatment and non-adherence.” (Participant No. 10, a center Manager).*

*“My father only performs routine clinical tests rather than more specialized ones like ultrasounds because they are so expensive.” (Participant No. 4, a patient’s daughter).*

*“The high cost of treatment, as well as the scarcity of some medications, such as insulin pens, contribute to patients’ non-adherence to treatment.” (Participant No. 6, a psychologist).*

**Therapeutic substitution:** Some patients with diabetes use less expensive medications instead of those prescribed by their physicians due to the high cost of some diabetic medications/procedures.

*“If the doctor orders an ultrasound or any other tests, I will not be able to comply with their request because of my financial situation.” (Participant No. 1, a patient).*

### Individual factors

Patients, their families, and healthcare providers all mentioned personal problems as a reason for treatment nonadherence. Inadequate knowledge about the disease process, interest in certain foods and misconceptions, as well as some problems that affect a person both mentally and physically, and certain dependencies make patients fail to adhere to an appropriate treatment.

**Insufficient information:** The lack of knowledge about diseases is one of the barriers to treatment adherence that nurses try to address.

*“Patients who are unaware of their own disease have poor treatment adherence.” (Participant No. 1, a nurse).*

**Interference of personal preferences with treatment recommendations:** The patient’s interest in certain foods can affect treatment adherence, making it difficult for the patient to stick to a diet.

*“My father does not believe in or follow any sort of diet. He enjoys eating fruit like watermelon and melon in the summertime.” (Participant No. 3, the patient’s daughter).*

**Incomplete information and misconceptions:** Patients, their families, and healthcare providers also mentioned misconceptions as a barrier to treatment adherence. Some people believe that the medication should be stopped or reduced in dosage while the disease heals.

*“When I am feeling better or have low blood sugar, I do not use my own insulin or take my night sugar pill.” (Participant No. 15, a patient).*

*“When a doctor recommends a patient who is taking a sugar pill that he or she needs to take insulin, the patient reacts negatively because he or she perceives it as a threat.” (Participant No. 4, a psychologist).*

*“Some patients with poor adherence believe that their diseases are inherited and that treatment is ineffective, and thus disregard staff’s advice.” (Participant No. 5, a nurse).*

**Table 2: Categories, subcategories, and codes of barriers to treatment adherence from the perspective of patients with type 2 diabetes**

Codes	Categories	Subcategories
Financial problems	Difficulty undergoing a course of treatment	Not performing tests or ultrasounds due to high cost and use of cheaper medications.
Individual factors	Incomplete information and misconceptions	Discontinuation of medications in case of relative recovery of the disease
	Emotional and psychological problems and concerns	Feeling helpless and afraid of the complications of the disease, suffering living conditions due to illness, being bored and tired of living conditions, depression caused by the death of a sister
	Physical problems	Impatience and lack of motivation to undergo a course of treatment Inability to move, hearing, vision, and heart problems and consequently dependence on family members to take medication
	Disease of other family members	A child with cancer and as a result nonuse of medications Spouse with diabetes and as a result no preparation of insulin
	Lack of attention and support of family	Lack of attention of children to medications, and as a result, the patient forgets to take medications, lack of attention and support from the patient's spouse and children; family does not cooperate with the patient in adhering to the diet, marital problems
	Loneliness	Not preparing and taking medicines because of loneliness
Problems related to the preparation and maintenance of medicine	Forgetfulness	Not taking some doses due to forgetfulness
	Problems related to insulin	Special conditions for insulin storage, insulin scarcity
Poor practice of healthcare providers	Multiple medications	Large number of medications used by the patient daily
	Doctor–patient relationship	Uncertainty about doctor's prescription, crowded offices
	Nurse–patient relationship	The inability of the patient to share problems with nursing staff

**Table 3: Categories, subcategories, and codes of barriers to treatment adherence among patients with type 2 diabetes from the perspective of patients' families**

Codes	Categories	Subcategories
Financial problems	Difficulty undergoing a course of treatment	Not performing tests or ultrasounds due to high cost, the high cost of insulin, and the inability of family members to provide it
Individual factors	Interference of personal preferences with treatment recommendations	Great interest in eating fruit
	Feelings of frustration and indifference of family	Not talking to and getting help from family members regarding treatment issues, disbelief in diet
	Individual dependencies	Patient dependence on the child due to disability, excessive dependence of the patient on family members, dependence on family members due to old age
	Loneliness	Patient living apart from the family
	Inattention and forgetfulness	Forgetfulness of the patient and family members and thus not taking medication

**Emotional and psychological problems and concerns:** Chronic diseases can lead to many psychological problems. In the study, interviewees talked about their feelings of disappointment and depression, as well as how they felt helpless.

*“I am tired of my illness, and my living condition is difficult for me.” (Participant No. 7, a patient).*

*“I am feeling very incapacitated. Medication and insulin injections are all being provided for me by my daughter.” (Participant No. 12, a middle-aged patient).*

*“I am not interested in treatment. If my children do not keep me in check, I will not take medicine or see a doctor.” (Participant No. 14, a depressed patient due to the death of her sister).*

*“Patients who do not improve after a course of treatment will become bored and tired, especially if they are trying to lose weight. Frustration and poor adherence are common outcomes when patients do not get the results they expected.” (Participant No. 2, a Center Manager).*

**Complications of the disease:** Both patients and healthcare providers mentioned type 2 diabetes complications as a reason for nonadherence to the treatment. Diabetes frequently results in complications, including neuropathy, diabetic foot syndrome, kidney failure, and diabetic eye disease. People's fear of becoming entangled in these complications makes it difficult for them to adhere to diets and medications.

*“Due to complications like neuropathy, patients become depressed and lose interest in their treatment adherence.” (Participant No. 9, a Center Manager).*

**Table 4: Categories, subcategories, and codes of barriers to treatment adherence among patients with type 2 diabetes from the perspective of healthcare providers**

Codes	Categories	Subcategories
Financial problems	Preparation of food	The inability of a person to prepare food recommended by doctors
	Difficulty undergoing a course of treatment	Expensive glucometer strips, expensive insulin
Individual factors	Insufficient information and misconceptions	Lack of knowledge of patients about their disease, thinking that the disease is inherited and the treatment is useless, negative patient thinking of changing pills to insulin
	Disease complications	Complications of the disease in a person such as neuropathy and subsequent depression prevent patients from adhering to medication and diet
	Home and family environment	Delaying insulin preparation
Scarcity and problems related to medication preparation	Problems related to insulin	
Poor practice of healthcare providers	Doctor-patient relationship	Doctor's inattention toward the patient's words, Doctor's behavior with the patient

*“Due to diabetes, my ears can hear very little. That’s why I don’t go to therapy because I hardly hear people’s words and no one has the patience to shout to hear my words.” (Participant No. 10, a male patient).*

**Physical problems and individual dependencies:** Physical problems and reliance on other family members are also barriers to treatment adherence among patients with diabetes. Older people are more likely to be dependent on other family members for their medication and food.

*“I cannot use my medication or inject my insulin on my own because of my foot pain, back pain, and vision problems. If my son does not help, I will be in trouble.” (Participant No. 16, an older patient).*

*“I suffer from a variety of diseases as a result of my diabetes. My eyes, ears, legs, and heart are all affected, and I cannot help myself without the help of my children.” (Participant No. 18, an older patient).*

*“My mother suffers from numerous physical problems, including back pain, foot pain, and vision problems, and she is unable to work. She resides downstairs in my house. I pay her a visit, but it is not something I can do on a regular basis. When I am not around, she will not take her medication.” (Participant No. 8, an older patient’s son).*

*“My mother is completely dependent on us, and without us, she would have no idea how to use her medication. This has created a problem for us because we, too, face numerous difficulties in our lives, and our mother’s expectations have caused us great anxiety.” (Participant No. 7, a patient’s daughter).*

*“As a full-time worker who visits my mother nightly, I have noticed that she has not taken her medication or has taken it inadvertently. I have no idea what to do at this point.” (Participant No. 10, an older patient’s son).*

**Home and family environment:** Patients with diabetes are less motivated to adhere to their medication and diet due to tension, disease, and conflicts between family members, and as a result, the course of treatment is less successful. Treatment adherence improves in patients who receive emotional support from other family members.

*“Since the diet is not observed at home, I have to eat food that my wife cooks.” (Participant No. 5, an older patient).*

*“Now that my husband has passed away, my children have stopped paying attention to me. I frequently neglect to take my medication because no one is there to remind or assist me.” (Participant No. 9, an older patient).*

*“My husband and children pay no attention to me. I am responsible for my own treatment. It is extremely difficult for me, and as a result, I visit the doctor less frequently and take fewer medications.” (Participant No. 13, an older patient).*

*“The emotional support of patients’ families is critical, and patients who do not adhere to their treatment have no one to lean on and are unconcerned about their illness, making them unmotivated.” (Participant No. 7, a psychologist).*

**Illness of other family members:** A person with diabetes who is also caring for a sick family member may be less likely to adhere to own treatment. The individual is unable to adhere to the treatment because of maternal emotions or increased treatment costs caused by the illness of another family member.

*“My child is battling cancer. Since his/her illness, I have completely neglected my own health and treatment.” (Participant No. 21, a patient).*

*“My spouse has diabetes as well. I am at a loss because I am unable to afford insulin. Many times, I do not inject at all or inject only one dose. Unfortunately, the doctor does not understand me.” (Participant No. 22, a middle-aged patient).*

**Lack of attention and family support:** Tensions and conflicts in the home and the lack of emotional support of other family members for the sick person are the main obstacles to the treatment’s nonadherence.

*"Family conflicts and marital quarrels aggravate my illness, necessitating additional medication that I am unable to afford." (Participant No. 3, a patient).*

**Loneliness:** Patients and their families reported that living alone was a barrier to treatment adherence.

*"I am unable to purchase medications because I live alone and do not wish to disturb my children." (Participant No. 4, a patient).*

*"Even though my mother lives far away, I try to keep up with her treatment in some way." (Participant No. 1, the patient's son).*

**Forgetfulness:** The timely administration of medication is critical in the management of diabetes disease. The patient and other family members' forgetfulness about medication use hampered the achievement of this objective. Due to their problems and busyness, family members often forget to remind their patients to take their medication.

*"A high level of forgetfulness prevents me from taking some of my medication." (Participant No. 6, an older patient).*

Forgetfulness of other family members was also one of the obstacles to treatment adherence. Due to modern urban life and the fact that the majority of people prefer to spend their time outdoors, family members often forget to remind their loved ones to take their medication as prescribed.

*"My mother frequently forgets to take her medication. We also forget to remind her to take her medication." (Participant No. 5, a patient's daughter).*

#### **Problems with the preparation and use of medicine**

One of the barriers to treatment adherence was problems with medication supply and consumption. Problems with the preparation, maintenance, and high cost of insulin, as well as the large number of medications that patients take, prevent them from adhering to the treatment.

**Problems with insulin:** A number of factors that contribute to treatment nonadherence among patients include the high cost of insulin, specialized storage requirements, delays in the preparation of insulin, and its scarcity.

*"The patient becomes bored as a result of insulin delays and high costs." (Participant No. 11, a nurse).*

*"When I am out and about, it is difficult to inject my insulin, which needs to be kept on ice." (Participant No. 2, a patient).*

*"Treatment non-adherence can be exacerbated by the scarcity of certain medications, such as insulin pens." (Participant No. 6, a psychologist).*

**Multiple medications:** Taking too many medications throughout the day is one of the difficulties people have in adhering to their treatment. Such patients feel exhausted and bored, and as a result, they stop taking them.

*"I have to take 15 to 16 pills a day, and I am completely spent." (Participant No. 11, a middle-aged patient).*

#### **Poor practice of the healthcare providers**

The patient–staff relationship presented as a significant barrier to treatment adherence. In order to help patients with diabetes adhere to their treatment regimens, healthcare providers must offer correct and constructive advice, as well as make recommendations for disease management.

**Crowded offices and medical centers:** One of the effective factors in not adhering to treatment was the congestion of medical centers and offices.

*"The doctor's office is too crowded for me to go because I am not patient. However, I have to go to the doctor's office to get my insulin; otherwise, I will not go or do a test." (Participant No. 17, an older patient).*

**Physician–patient relationship:** With so many people visiting medical centers and offices, doctors are unable to spend more time with patients discussing their medical problems and concerns. Therefore, patients become angry and upset and do not go to the doctor's office.

*"Doctor-patient interactions are critical, and if the doctor only pays attention to prescribing and ignores the patient's words, the patient will be reluctant to visit the doctor in the future." (Participant No. 8, a nurse).*

Lack of trust in the doctor's words and prescriptions was also a reason for nonadherence to treatment regimens.

*"What is the point of following the doctor's orders? Perhaps the doctor wants to push me into a hole, but when I look at my condition, the doctor says something completely irrelevant to my situation." (Participant No. 20, an angry middle-aged patient).*

**Patient–nurse relationship:** Failure to seek help and communicate with the nursing staff was a problem among many patients.

*"The clinic staff are strangers to me, so I am unable to open up to them about my problems." (Participant No. 8, a middle-aged patient).*



## Discussion

Study results revealed that people with type 2 diabetes may have difficulty adhering to their treatment due to a variety of causes. Patients with type 2 diabetes were unable to adhere to their treatment because of financial problems, personal factors, problems related to medication preparation, maintenance, and poor healthcare team practice.

Patients are unable to provide medications because of the high cost of treatment, or they have to take less expensive medications. Adopting some self-care practices, such as having a healthy diet and getting enough physical activity, are difficult to maintain because of the associated costs, such as purchasing a glucometer and regular blood sugar monitoring.<sup>[24]</sup> The cost of treatment is a disincentive for patients with diabetes who have a low socioeconomic status or who do not have access to healthcare insurance.<sup>[25]</sup> Many studies also considered economic problems as a barrier to treatment adherence.<sup>[26-28]</sup>

According to the study results, some patients stop taking their medications because they believe that they have made a significant recovery, so the course of treatment is not going well. According to the findings of the current study, patients may have difficulty adhering to treatment due to a lack of understanding and misconceptions, which were also stated in Alwazae *et al.* (2019)<sup>[25]</sup> and Huang *et al.* (2021) studies.<sup>[29]</sup> Patients may have misconceptions about their treatment adherence, so nurses and healthcare teams should pay special attention to address these misconceptions and enhance patient's treatment adherence by honoring cultural values. To help patients adhere to treatment, they can hold sessions with the goal of creating close communication and discussing their values.<sup>[26]</sup>

Patients in the present study and related studies addressed psychological and emotional problems, a sense of helplessness and fear of the consequences of the disease, bad living conditions owing to illness, despair, impatience, and lack of enthusiasm during the course of treatment.<sup>[24,29-31]</sup> According to these findings, patients who have experienced stressful events are more likely to fail to adhere to treatment. Depression and stress can also have an impact on treatment adherence.

Patients also mentioned an excessive reliance on other family members, a family member's illness, loneliness, and forgetfulness. According to previous research, including that of Mostafavi *et al.*<sup>[32]</sup> and Dehvan *et al.*,<sup>[24]</sup> treatment adherence in patients was hindered by family members' problems and memory challenges. Lack of attention and support of family members from the sick

person was another obstacle to treatment adherence from the patients' point of view. It is not uncommon for people with type 2 diabetes to encounter problems relating to their families. The inattention of other family members to the patients' diet, particularly female patients, causes them to eat the same foods as the rest of the family. Women's failure to fulfill their family roles and their husbands' lack of behavioral and emotional support undoubtedly bother them in life, and their cooking is strongly influenced by their husbands or children's preferences.<sup>[26]</sup> Mukona *et al.* (2017),<sup>[33]</sup> Pamungkas *et al.* (2020),<sup>[34]</sup> and McBrien *et al.* (2017)<sup>[35]</sup> also reported a lack of family, peer, and community support as barriers to treatment adherence. Thus, daily challenges in life have an effect on how patients with diabetes interact with their disease and treatment course, and educating patients' families, who serve as the patient's primary caregivers, can be critical in controlling the disease and promoting patient's adherence to treatment.

Other chronic conditions and numerous medication uses were additional factors that contributed to a person with type 2 diabetes failing to adhere to treatment. When a person is taking many medications concurrently, they may develop an aversion to one of the medications, resulting in its withdrawal or dose adjustment. Additionally, treating any disease has an effect on other conditions and may interfere with diabetes treatment. Diseases such as knee arthritis, hypertension, hyperlipidemia, and spinal disease may exacerbate the negative effects of diabetic medications and need the patient's medication adjustment.<sup>[26]</sup> These findings corroborated those of Dehvan *et al.* (2015),<sup>[24]</sup> who identified concurrent use of multiple medications as the primary inhibitor of adherence to the treatment regimen.

Patients also rated inadequate healthcare team practices as a major barrier to treatment adherence. Diabetes patients' skepticism of physicians' recommendations, the crowdedness of offices, and ineffective communication with patients are just a few of the difficulties that healthcare practitioners must address. Other studies have found that the qualities of the healthcare team and system, their practice, and their interaction with patients all have a direct effect on medication adherence among patients with type 2 diabetes.<sup>[2,4,7,27,30,32]</sup> According to the findings of the present study, financial problems and some personal factors were the two main categories identified from the family perspective of patients with type 2 diabetes.

Financial problems have always been a major source for patients with diabetes.<sup>[32,35,36]</sup> Individuals, who have low or no income, typically avoid medical centers, particularly private ones, in order to minimize

their out-of-pocket payments. These individuals are uninsured, are the heads of families, and have a low income, which means they lower the cost of treatment and medicine to meet other expenses. If a person is unable to pay for their therapy, they must rely on other family members. As noted in the current study, family members of patients with diabetes struggled to cover the expenses associated with their treatments, prepare medicines, and perform tests, resulting in poor treatment adherence in patients with type 2 diabetes. Given that financial problems would affect other aspects of therapy, including training,<sup>[35]</sup> it is critical to pay specific attention to this issue throughout interventions.

Another issue raised by family members is a person's proclivity for certain meals and a lack of diet compliance. They observed that patients were unable to manage their eating behavior due to a strong desire to consume a certain meal and so did not adhere to their diet completely. Açıl *et al.*<sup>[37]</sup> (2019) also emphasized diet nonadherence as a major issue for patients with diabetes. As a result, health providers must talk to patients about their eating habits and preferences and help them achieve lifestyle adjustments. Patients can participate in the decision-making process when they work with health professionals who specialize in diabetes and self-management.

The present study noted that patients did not communicate with other family members about their problems and concerns regarding their therapy, and that some patients were overly reliant on other family members. Some patients believed that they will become a burden on their family if they discuss their worries and concerns with other family members. This is especially prevalent in older adults who lack an income and live with their children, and as a result, they will fail to adhere to their treatment. In comparison, some patients are extremely reliant on other family members to perform minor daily duties due to old age, inadequate literacy, and a lack of self-confidence. Other family members may not pay sufficient attention to the patients' medications, which was also mentioned as a barrier to treatment adherence in this study. Family members can ease the path for the patient to communicate with them about treatment-related challenges and concerns. Additionally, they can organize and manage time to assist patients in adhering to their medication regimen. Mishalia *et al.*<sup>[38]</sup> demonstrated that family awareness played a role in diabetes control, which might improve patients' quality of life. Bamari *et al.*<sup>[39]</sup> also showed that family support for patients with diabetes was useful in controlling the disease and assisting the patient in accepting the consequences of their disease.

Therefore, patients with diabetes need home care because they may have difficulty accessing health

care. Patients can be more successful in their treatment adherence if they gain more information through special educational methods, become empowered by nursing interventions, and their family members engage in diabetes management. From the perspective of healthcare providers, financial problems, personal factors, scarcity and problems in medication supply, and poor practice of the healthcare team were the most important reasons for treatment nonadherence among patients with type 2 diabetes.

According to healthcare providers, one of the main needs of patients is to receive a diet that suits their living and financial conditions. Therefore, the healthcare team must consider this issue in their nutritional prescriptions and guidelines. These results were in line with the results of Açıl *et al.*<sup>[37]</sup> who reported that nutritional recommendations were inappropriate for patients' lifestyle. Wilkinson *et al.*<sup>[40]</sup> also found that patients with diabetes had financial problems in following a proper diet.

Another factor of nonadherence to treatment among healthcare providers was some misconceptions about the disease. Some patients think that diabetes is an inherited disease, so diet and medication have no effect on it. Nurses and healthcare teams should try to correct incorrect beliefs that are not scientific and are based only on the wrong thoughts and should promote adherence to treatment in such patients.

According to the study results, mental diabetes complications including depression and related problems affect adherence to the treatment among patients with diabetes. An epidemiological study has shown that depression is more common in people with diabetes, regardless of whether or not diabetes is diagnosed. This study showed that anxiety was higher only in participants who were aware of their diabetes.<sup>[41]</sup> Therefore, the psychological burden of the disease may play an important role in stimulating anxiety and depression in the patients. However, depression is more common among patients with diabetes,<sup>[7,24]</sup> which can be due to the disease's nature and its chronicity, living conditions, medications, and some complications such as diabetic neuropathy.

Evidence suggests that the prevalence of depression has increased moderately in patients with prediabetes and undiagnosed diabetes, and significantly increased in patients with diagnosed diabetes compared with healthy individuals.<sup>[42]</sup> Depression and anxiety in patients with diabetes worsens the prognosis of diabetes, increases noncompliance with medical treatment, reduces the quality of life, and increases mortality and morbidity.<sup>[43]</sup> There appears to be a mutual relationship between

diabetes and depression that may have common biological mechanisms, the understanding of which can cause better treatment and improve outcomes for these pathologies.<sup>[44]</sup>

The home and family environment were other factors mentioned by healthcare providers as a barrier to treatment adherence. The support of family members is important for managing diabetes. Family members' awareness of diabetes can affect patients' self-efficacy. Patients consider their family members excellent assistants in making decisions about their illness, especially regarding diet adherence and adaptation to disease.<sup>[37]</sup> Therefore, it is recommended that the knowledge of family members be improved through training programs. In a systematic review of qualitative studies, patients with diabetes had difficulty adhering to their diets while staying with people without dietary restrictions.<sup>[40]</sup> Therefore, the family can improve treatment adherence among patients.

Families should be involved in the patient's self-care process to increase their adherence to treatment, and educational programs should change the attitudes of patients and their families.<sup>[24]</sup>

The poor practice of healthcare providers was another factor in the treatment nonadherence among patients with diabetes. The results of the present study showed that the physician did not pay attention to the patient's words and did not behave well with patients. As patients cannot communicate continuously and usefully with their doctors, they stop continuing to see a doctor or reduce the number of their visits. Patients need counseling and interaction with the healthcare team, the necessary recommendations for disease management, and motivation to adhere to the treatment.<sup>[4]</sup> Sometimes, physicians' improper attitude and behavior make patients unmotivated, so they quit their treatment. Therefore, the practice of the healthcare team is one of the most important factors in adhering to treatment among patients with diabetes. According to these results, training in communication techniques, especially effective listening skills, will play an effective role in this regard.<sup>[37]</sup>

One of the strengths of this study was assessing the barriers to treatment adherence from the perspectives of patients, their family members, and healthcare providers that play a key role in adherence to treatment among diabetic patients. By comparing the perspectives of patients, their families, and healthcare providers, a set of common challenges about adhering to proper diet and medication that may encounter were obtained. It can be concluded that tailoring a three-armed family-based intervention can be beneficial.

However, this study had some limitations. Some patients with type 2 diabetes were old, family members and healthcare providers were busy, which made it difficult to coordinate interview hours, and the interviews with the patients were difficult due to the virtual interviews. Another limitation was that the researchers were only able to examine the patients, their families, and the healthcare providers of a few diabetes centers, which can affect on a generalization of the study results.

The study findings can be used to empower diabetic patients with limited health literacy to treatment adherence. Identifying the factors affecting adherence to treatment in Iran helps nurses and other healthcare providers who deal with Iranian patients with type 2 diabetes to recognize and solve barriers to treatment adherence.

## Conclusion

The study results evaluated the viewpoints of patients with type 2 diabetes, their families, and healthcare providers on barriers to treatment adherence. According to the results, barriers to treatment adherence among patients with type 2 diabetes were influenced by financial problems, personal factors, and poor practice of the healthcare providers. Therefore, effective steps can be taken to empower patients and their families in promoting adherence to the treatment among patients with type 2 diabetes with limited health literacy using planning and implementing educational-supportive interventions focusing on the commonly mentioned barriers.

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## Declaration of patient consent

The authors certify that they have obtained all appropriate patient consent forms. In the form, the patient(s) has/have given his/her/their consent for his/her/their images and other clinical information to be reported in the journal. The patients understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

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## Conflicts of interest

There are no conflicts of interest.

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