



Caring for Children with Diabetes in the Shadow of COVID-19 Pandemic: Challenges Experienced by Iranian Mothers

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Abstract

Background: Diabetes Mellitus is one of the chronic diseases of childhood that needs long-term care and follow-up. The participation of the family, especially mothers, in caring for their child seems essential. This study aimed to investigate the challenges of Iranian mothers in caring for their children with Type 1 diabetes mellitus during the outbreak of COVID-19.

Methods: This qualitative study was conducted on 22 participants who engaged in taking care of children with diabetes mellitus. Purposeful and snowball sampling were used to select the participants.

Results: The main theme of “diabetes control in the shadow of the COVID-19” and three categories emerged from data analysis.

Conclusion: Lack of taking the child to the doctor during the COVID-19 the pandemic impacted the management of diabetes in their child. Therefore, having a virtual communication channel between the family of diabetic children and the health care professionals could be helpful for managing the children’s disease.

Keywords: Caring, Children, COVID-9 pandemic, Qualitative study, Type 1 diabetes mellitus

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Introduction

One of the most common chronic diseases in children requiring long-term care is Type 1 Diabetes Mellitus (1). According to available statistics, more than half a million children and adolescents under age 14 in the world have this type of diabetes (2). It is estimated that this number will double by 2030 (3). In Iran, there are more than 200,000 patients with Type 1 Diabetes Mellitus (4). Type 1 Diabetes Mellitus or insulin-dependent diabetes type A which is due to autoimmune pancreas beta-cell destruction (5) is the most common endocrine disease in children (6). Hyperglycemia, due to improper management, leads to failure of various organs of the body, including heart, brain, kidneys, eyes, and nerves (7). Therefore, children and adolescents with diabetes need special health care. To provide these care services, the cooperation and assistance of family members, especially mothers, is essential (8). Smith *et al* highlighted the importance of the caring role of mothers and other family members for the management of child diabetes (9). Among family members, mothers are most involved in caring for a sick child and help them to adapt and manage the chronic disease (10). Regarding disease management, Chiang *et al*, found that lifestyle changes are effective in maintaining health, preventing cardiovascular diseases, and regulating blood sugar in children with diabetes mellitus (11). This might not be possible unless the mother involves herself in accepting the role of caring for children (12). A mother's role is influenced by various factors during the process of accepting the role of a caregiver. Dhada and Blackbeard outlined some challenges of caregivers of children with diabetes mellitus such as chronic grief, role acceptance, and adaptation, physical and emotional stress, familiarity with care, collaboration with health care providers, seeking supportive systems, and establishing social interactions (13). In a qualitative study conducted in Netherlands, Raaijmakers *et al* highlighted the significance of the continuity of care management, especially in chronic diseases such as diabetes. The results showed that caring for these patients requires optimal coordination and communication among various health care professionals and organizations (14). In addition to current barriers and issues in the management of diabetes mellitus, the emergence of

COVID-19 and social distancing could impact the management of diabetes mellitus in children (15-16). According to the literature review, the role of mothers in caring for children depends on the context and is influenced by various cultural and social factors. Given that no study was found considering the experiences of mothers caring for children with diabetes, this study was conducted to explore the lived experiences of mothers caring for children with diabetes during the COVID-19 pandemic.

Materials and Methods

This qualitative study was conducted using the thematic analysis method. Content analysis is a popular method for analyzing qualitative data and is able to show patterns in data (17). Data were collected from 2019 to 2020. Participants of the study included 22 mothers who care for children with diabetes mellitus. Participants were selected from two university-affiliated hospitals in Urmia (the capital of West Azerbaijan Province, Iran) and the Urmia Diabetes Association. Inclusion criteria were as follows: having a child with Type 1 Diabetes Mellitus approved by a pediatrician and being diagnosed within last year and willingness and ability to communicate and share their experiences with researchers. Exclusion criteria included the withdrawal of the participant during the interview process and the unwillingness to share their information after the interview. The first participant was purposefully entered into the study by cooperating with the head of the pediatric endocrinology department. She was then asked to introduce other mothers of children with a similar disease. Similarly, other participants were selected by the snowball sampling method. Most of the participants were recruited based on emerging codes during the data analysis process. Maximum diversity was considered regarding mother and child's age, mother's education level, number of children in the family, marital status, employment status, birth order, child's sex, and duration of child's disease. Due to the familiarity of the head of the department with the mothers of diabetic children, the first participants with rich care experience were selected by her guide. After analyzing and extracting codes and primary categories, new participants were selected. Sampling was continued until data saturation was

achieved, and no new class was found. Finally, two more interviews were conducted to ensure that data saturation had been achieved.

Data collection

Data collection was performed utilizing semi-structured in-depth face-to-face interviews. The purpose of the study was explained to each participant individually, and informed written consent was obtained from them. The time and location of the interviews were determined by the participants. The first interviews were conducted according to the interview guide prepared by the research team. The research team consisted of a nursing Ph.D. student with 29 years of clinical and educational experience, an assistant professor of nursing specializing in qualitative research, and a professor of nursing specializing in qualitative research and family-centered care. The interviews began with a general question and gradually moved on to deep questions. Examples of interview questions are in the following:

- 1) *"Please talk about your experience of living with a child with diabetes."*
- 2) *"Who helps you care for your child?"*
- 3) *"What problems did you face while caring for your child?"*
- 4) *"How do you play the role of caring for your sick child during the COVID-19 pandemic?"*

If there was ambiguity in the participants' answers or further explanation was needed, probing questions were asked such as *"Can you explain more?"* or *"Could you give an example to clarify what you mean?"*. Each interview was ended with the question *"Would you like to add anything more?"* Each interview lasted from 25 to 84 minutes. The mean duration of all the interviews was 47.26 minutes. At the end of each interview, the recorded interview was transcribed and typed word by word.

Data analysis

Data were analyzed using the thematic analysis method developed by Braun and Clarke (17). They introduced content analysis as a way to identify, analyze, and report patterns (themes) in data. In the first step, the first author got acquainted with the data

through repeatedly reading the text of the interviews in search of meanings. In the next step, data were coded. An initial list of ideas about semantic units (whole interview, paragraphs, or sentences) was compiled and each idea was labeled with a code. The initial codes were generated by the first author. The third step was to search for categories. At this step, potential categories were generated by sorting and combining the relevant codes. The initial categories were formed by the first author and discussed infrequent sessions held by all authors. In the fourth step, the categories were examined and the main theme was formed. The categories and the main theme were named in the fifth step. The labels of codes and categories were discussed and revised several times in the research team meetings to agree on them.

To ensure the rigor of the study, Lincoln and Guba's criteria including credibility, transferability, dependability, and confirmability were utilized (18). In order to gain credibility, some of the written interviews with codes and categories were reviewed by three professors of nursing who were experts in the field of qualitative research in nursing (peer-debriefing). In addition, interviews and codes were presented to four participants to ensure that the findings matched the participants' perceptions and interpretations (member check). Moreover, to improve the study's credibility, prolonged engagement with the data and limiting the review of similar texts at the beginning of the study were conducted to reduce the possibility of bias in all steps of collection, analysis, and coding.

To achieve the dependability criteria, the data were provided to an external reviewer who was familiar with both the clinical environment and the qualitative research but was not a member of the research team. To determine the confirmability, classes were provided to two researchers familiar with qualitative research, and their opinions and interpretations, which showed a lot of agreement, were compared. Transferability refers to the extent to which qualitative data is transferred to other domains or groups. To achieve this criterion, all the variables of the study, including the participants' characteristics and the research settings, were fully and clearly explained so that the reader could decide on the possibility of generalizing and transferring the results to similar contexts.

Ethical Considerations

This study was conducted after being approved by the Ethics Committee of Urmia University of Medical Sciences (ethical code: IR.UMSU.REC.1397.284). All participants were asked for permission to record the interviews. Participants were assured about the confidentiality of their information, voluntary participation in the study, the right to withdraw from the study at any time prior to publication of the results, and lack of negative consequences on receiving health care services due to their withdrawal. The informed consent form was obtained from all the participants.

Results

A total of (22) mothers of children with Type 1 Diabetes Mellitus participated in this study. They were aged 30-48 years old. Most of them (84.21%) were housewives, 36.84% had a high school diploma or higher degree, and 84.21% lived with their spouse. The number of children in families who participated

in this study differed from 1 to 4, and 45% of the participants had two children. The mean age of the children was 12.25 ± 2 , most of them (40%) were first child, 65% were girls, and the mean duration of children’s disease was 40 ± 52 months.

The analysis showed the main theme of “diabetes control in the shadow of the COVID-19” and three categories of “being on the path to diabetes control”, “cautious care in the shadow of the Covid-19 pandemic”, and “relative inefficiency of the health care system” (Figure 1).

Being on the path to diabetes control

According to the participants, mothers recognize the symptoms of the disease, acquire the necessary ability to manage the child’s blood sugar, and adapt to the disease gradually and over time. Accordingly, their referral to the hospital due to changes in their child’s blood sugar is reduced, increasing their satisfaction.

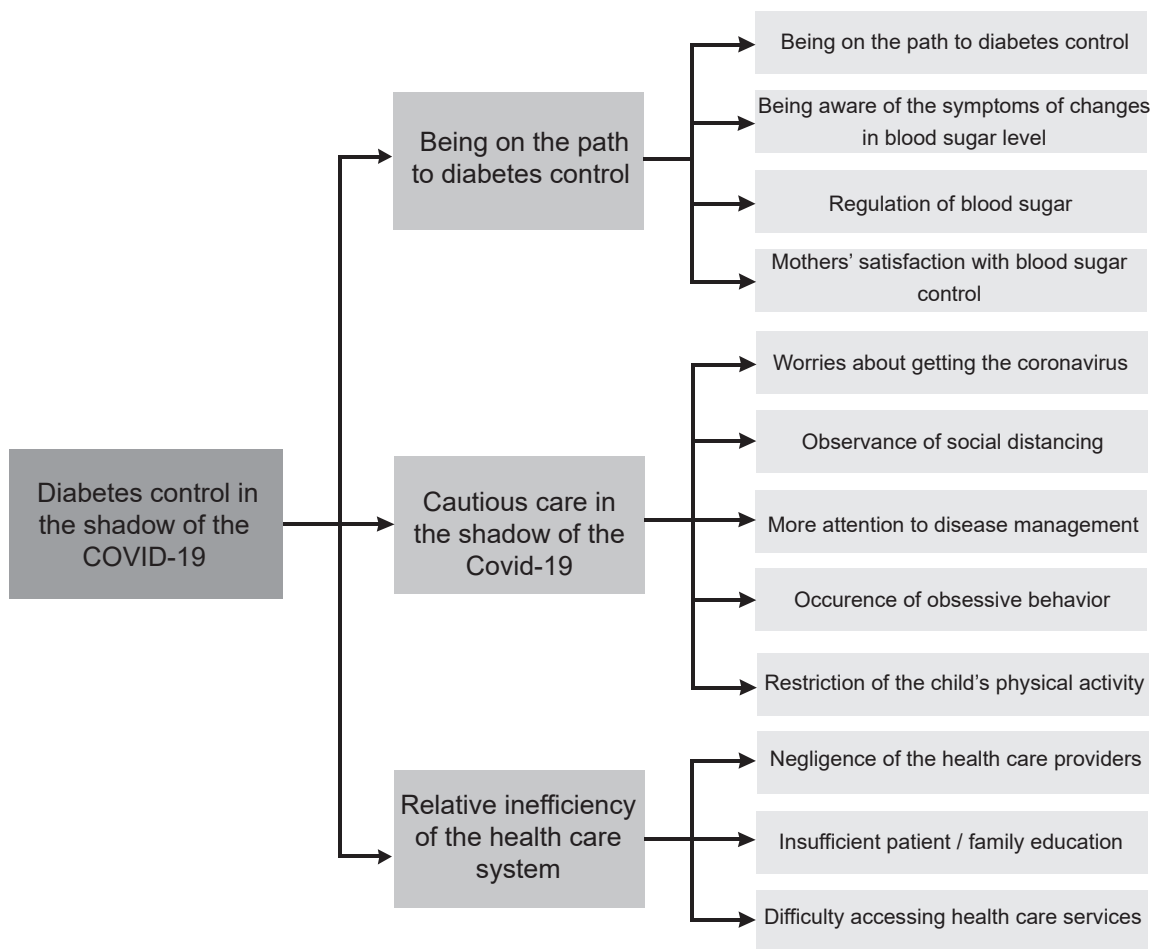


Figure 1. Diabetes control in the shadow of the COVID-19.

Improving the mothers' ability over time:

Participants considered the passage of time as an important factor in increasing the ability to care for and manage the disease. Mothers gradually adapt to the disease and refer to the hospital less after recognizing the symptoms of changes in blood sugar and using blood sugar checking tools. One of the participants asserted:

"We used to go to the hospital a lot. But now, we go to the hospital less as my child has learned about her disease. For example, when her blood sugar drops, she knows how to manage it. Second, we have a glucometer." (P6)

Being aware of the symptoms of changes in blood sugar level:

Recognizing the symptoms of changes in blood sugar level is an important step in managing diabetes. All participants noted the importance of recognizing these symptoms by mothers and the child.

"Vomiting and drinking water over and over shows the lower blood sugar... When her blood sugar level is high, she vomits and drinks a lot of water. But when her blood sugar is low, she feels lightheaded and shaky." (P22).

"When his blood sugar drops, he becomes very lethargic, his heart beats fast. When his blood sugar rises, his lips become dry, he has shortness of breath, and this is how I notice his blood sugar is high or low." (P9)

Regulating blood sugar:

Regulating blood sugar was one of the problems experienced by mothers. With the knowledge gained gradually, they were able to control the child's blood sugar level within an acceptable range. One participant noted the importance of maintaining composure in order to better manage the child's condition when his or her blood sugar drops:

"When this happens, you should not get nervous. I try to be calm, give her syrup, and massage her body. I wait for 15 minutes and if she does not feel better, I will give syrup once again. Within an hour, her blood sugar will get back to normal." (P1)

Mother's satisfaction with blood sugar control:

Feeling satisfied and happy with the regulation of blood sugar and the course of recovery, which indicates the optimality of care, gives the mother more energy and increases her ability to continue on the path. The reflection of this feeling was quite evident in their words.

"When I check and see her blood sugar is normal, I really feel happy." (P4)

Cautious care in the shadow of the Covid-19 pandemic

In the present study, caregivers faced several challenges during the COVID-19 pandemic. Mothers' concern about their child developing COVID-19 disease led to the application of various measures. Some of these measures resulted in the child's anger due to limiting the child's communication with his/her peers. These challenges sometimes result in decisions that may threaten the child's health.

Worries about being infected with the coronavirus:

One of the main concerns of mothers was the fear of being infected with the coronavirus by children. They believed that the outbreak of COVID-19 had hampered patients' easy access to health care services. Mothers avoided referring to the doctor, even for routine control of the child's condition, thinking that the doctor's office is contaminated with the COVID-19 virus since such environments are crowded.

"Because of coronavirus, I'm more careful about my child. I should take her to the doctor for the follow-up, but I am scared of this virus. The doctor's office is crowded and my child gets coronavirus." (P9)

Observance of social distancing:

Participants took some precautions out of fear of infecting themselves or their family with the coronavirus and the possibility of transmitting it to their child with diabetes. One of these precautions was restricting interactions with

family and others.

“To be honest, coronavirus disease has prevented us to go to gatherings. We avoid going to our relatives’ houses. ... We all use masks first for the sake of my child and then for ourselves. Since the beginning of coronavirus, my daughter has not had the slightest sickness or cold.” (P4)

More attention to disease management:

Some participants believed that with the onset of COVID-19 disease, they were more careful in regulating blood sugar so that their patient did not need to refer to the hospital. Although this practice was performed upon the doctor’s advice, inaccuracies and possibly incorrect calculations of insulin doses for a long time may lead to negative consequences.

“Coronavirus has made us very careful in controlling her blood sugar. I am worried if her blood sugar is not controlled correctly, her immune system might be weakened and she might get coronavirus disease; then, the infection might spread throughout her body, and we cannot do anything for her. In fact, I have increased her insulin dose so that she eats more fruits. This is again due to coronavirus disease; I did that to strengthen her immune system.” (P4)

With respect to increasing the precision to prevent the child from being infected with COVID-19, another participant stated:

“I got coronavirus myself and was hospitalized for a week. When I came home, I did not leave the room for a month, I was careful not to transmit this disease to my child. ... Our whole life has been changed. I can’t take him anywhere due to fear of coronavirus. I think all places are contaminated with this virus.” (P9)

Occurrence of obsessive behavior:

Fear of developing the infection and disease caused by the COVID-19 virus has led to some preventive measures. These measures sometimes go beyond reason and turn into obsessive-compulsive behavior.

“Since the outbreak of coronavirus, my child keeps asking: do we have a disinfectant mom? I want to rub it on my hands. She scrubs her hands with washing liquid every minute.” (P13)

Restriction of the child’s physical activity:

Due to the direct effect of physical activity on blood sugar levels, it is necessary for caregivers to consider its role. Now, if this issue is not addressed and the amount of calories received is not adjusted with the child’s activity, it can lead to a decrease or increase in blood sugar and the child’s malaise.

“Before coronavirus, he was very active outside and was cycling and his blood sugar was ok. But now, because of this disease, I do not let him go out, he stays at home playing computer games, and his blood sugar goes up.” (P15)

Referring to the impact of the restrictions caused by the COVID-19 pandemic on her child, a participant said:

“Children do not go to school these days because of coronavirus. They are staying at home. On the one hand, it is good because I’m no longer worried about him getting this disease because he is always with me. On the other hand, my child gets nervous, because he is always at home and there is no one to play with him.” (P21)

The relative inefficiency of the health care system

Despite the important and beneficial role of the health care system, the participants pointed out some of the shortcomings of this system and expressed their dissatisfaction. One of these shortcomings was the unprofessional behavior of some members of the health care team in dealing with the family, especially mothers. Lack of timely diagnosis and proper treatment of the child in outpatient treatment centers was another issue that led to child deterioration and even going to coma. Despite the active involvement of the treatment team in improving the knowledge and skills of caregivers and patients, illiterate participants noted the ineffectiveness of the training provided by the treatment team.

Negligence of the health care providers:

Lack of timely diagnosis and proper treatment of the child is one of the problems associated with the health care team that can have irreparable consequences.

“I brought him there. The doctor visited him, gave

him two syrups, and said there is nothing special. I took him home and gave him the syrup at night. In the morning when he woke up, he vomited a lot, his face turned white, he became lethargic. He could not walk. When we arrived at the hospital, three or four nurses came, asked a few questions, tested my child, and said he had diabetes.” (P11)

“The doctor checked her blood pressure and said that her blood pressure had dropped. He did not understand that her blood sugar was very high. My child was shaking like this (showing how the child was shaking).” (P10)

Insufficient patient/family education:

Some participants pointed to deficiencies in the training provided by the health care team, especially by their physicians.

He (the doctor) looks at my child’s test and says goodbye! Come back three months later. He does not say anymore. I ask ‘does it decrease or increase’? What are we going to do? He becomes nervous. We should not ask him too many questions.” (P3)

Difficulty accessing health care services:

In the COVID-19 pandemic that needs to avoid being in crowded places, another concern of mothers was the problems related to easy access to the health care system.

“Now I have to go to the doctor to check my child’s blood sugar. I can’t take her to the doctor’s office due to fear of the coronavirus. If the doctor’s office is crowded, my child may get coronavirus. If she gets coronavirus, what can I do? I’m really confused.” (P14)

Due to the fact that the virtual response system of physicians in Iran is not yet fully established, receiving medical advice by phone or online is very limited.

“The problem we have is that we cannot talk to the doctor of my son’s. Nowadays, we are afraid of going to the doctor’s office due to coronavirus.” (P15).

Another participant, who was concerned about the impact of the pandemic on easy access to insulin, said:

“I am all worried about my daughter’s medicines. I

do not know what we should do if COVID-19 lasts too long and the children cannot get enough medicine.” (P22)

Discussion

This study examined disease management in mothers of children with type 1 diabetes. The analysis of the interviews suggested that mothers of children with diabetes were suddenly plunged into a difficult situation resulted from a chronic and unknown disease. Living with caring stress and lack of sufficient knowledge at the onset of their child’s diagnosis indicated the need of caregivers to receive support in various aspects of care, including knowledge of blood sugar, diet, and physical activity control, as well as financial and emotional aspects.

Proper control and management of diabetes require planning and goal setting¹⁹. The participants of this study addressed time as an effective factor in managing their child’s disease. They owed acceptance and adaptation to diabetes as well as learning how to care for the passing of time. Participants in the present study stated that after learning the relevant training, recognizing the signs of changes in blood sugar of the child, and being aware of the necessary measures, they were able to take care of their child better. Participants in the study also noted the need to follow doctors’ instructions considering insulin dosage, diet, physical activity, and regular monitoring of the child’s condition to achieve balanced blood sugar. In line with our findings, other studies highlighted the importance of diet, exercise, and the continuous monitoring of blood sugar as powerful and motivating measures for optimal regulation of blood sugar (11,20). In a cross-sectional descriptive study conducted on 120 Brazilian children and adolescents, Fortins *et al* highlighted the need for collaboration between professionals and family members to achieve satisfactory blood sugar control (21). In the present study, mothers reported their high satisfaction with the results of care provided. Lawton *et al* were the first to introduce the term “satisfaction” as one of the main dimensions of caregiver overall evaluation of care, which implies an understanding

of the desirability of care. In this regard, Labra *et al* conducted a study in three countries of Spain, the Netherlands, and Denmark and found that caregiver's family relationship with a care recipient was the main predictor of satisfaction with care (22). Findings of a study by Dhada and Blackbeard, on 14 caregivers of children with Type 1 Diabetes Mellitus in South Africa showed that caregivers' attitudes toward counseling provided by the treatment team were positive and satisfied. They also indicated that the care ability of the caregiver and the treatment team increased over time to the point where they reached satisfaction (13).

During the COVID-19 pandemic, some groups are more at risk than others, called high-risk groups. Patients with diabetes are also among this group. According to the results, the participants in this study refused to refer to medical centers or doctors' offices for periodic monitoring of their child's condition due to fear of their child developing COVID-19 disease. This practice has been observed in other countries in addition to Iran. For instance, findings of Klatman *et al*'s study on the challenges of patients with Type 1 Diabetes Mellitus during the COVID-19 pandemic represented that routine referrals of individuals with Type 1 Diabetes Mellitus to clinics decreased in different countries due to fear of developing this disease (23).

Participants in the study also limited their social interactions to prevent their child from developing COVID-19 disease. Findings of another study by Mirkazehi Rigi *et al* on the challenges and strategies to deal with COVID-19 in Iran indicated the need for self-care as the most useful measure (16). Since patients with diabetes have a higher chance of developing COVID-19 disease due to their underlying disease, our participants stressed the need for more careful management of diabetes. In their study in Iran, Firouzkouhi *et al* pointed out that the need to follow health protocols and stay at home increased the likelihood of calorie imbalance in these patients. Therefore, all patients, especially patients with type 1 diabetes, are advised to increase the frequency of blood glucose monitoring (24). According to World Health

Organization, the prevalence of mental disorders is increasing in the world (25). Some patients, including patients with diabetes, are at higher risk of developing mental disorders. For instance, Alizadeh *et al* studied the relationship between obsessive-compulsive disorder and glycemic control in 400 patients with diabetes in Iran. They found that almost half of their participants had a symptom of obsessive-compulsive disorder (26).

The results of the present study indicated the incidence of obsessive-compulsive disorder in children with diabetes during the COVID-19 pandemic, which is consistent with the results of a study by Jethwani *et al* in India. They stated that fear of COVID-19, closure of schools and colleges, and restrictions imposed following forced closure might affect the mental health of patients with diabetes, increasing the risk of mental health problems in them (27).

The findings of the present study also indicated that children's physical activity was restricted due to limited presence outside the house. Due to the pandemic nature of the disease, these restrictions exist worldwide. Due to such limitations, different studies have offered different recommendations for preventing the consequences of physical inactivity in these patients. Chowdhury and Goswami conducted a review study to address the problems of diabetes management in pandemic and outlined the recommendations made in studies for optimal disease control as follows: maintaining a regular schedule and being physically active, providing the necessary tools to manage the disease, and encouraging physical activity at home (*e.g.*, weight lifting, jump rope, and online training). They concluded that physical activity, in addition to regulating blood sugar, was also psychologically helpful, reduced stress and anxiety, and improved mood and sleep quality (28). Jethwani *et al* also noted in their study the negative consequences of limited physical activity in children with diabetes (27).

The task of the treatment team is to provide accurate and understandable information using a method that is acceptable to patients and their companions. However, some participants downplayed the role of

physicians and nurses in providing patient education and complained about it. Ghane *et al* studied 76 caregivers of hemodialysis patients in Iran and noted the inefficiency of the health care system. They concluded that caregivers were considered as the most important source for patient care in most health care programs, but less attention was paid to their problems (29). Abdoli *et al* argued that inefficiency of the health care system was one of the most important barriers to empowerment of people with diabetes (30). Findings of another study on women caring for the family in Canada showed that caregivers experienced challenges due to unsupported interactions with the health care team, negative emotions, mistrust, and lack of power (31).

Some participants pointed out the shortcomings in the training provided by the treatment team, especially physician treating their children. In line with the findings of the present study, Mousavizadeh *et al* identified the poor performance of the treatment team in disease management, such as providing incomplete and contradictory information as well as lack of cooperation between treatment team members, as one of the most important barriers against patients' adherence to treatment (32). Abazeri *et al*, in their qualitative study in Iran on nurses responsible for educating patients with diabetes, addressed the investment in the management of diabetes education. They identified three main themes, including inexperienced trainers, unstructured training, and unmanaged training (33). Participants in the present study also noted the inadequacy of training provided by the treatment team. In a study by Khandan *et al* in Iran, mothers pointed to the inadequacy of training provided by medical staff and stated that they had to use other resources, such as the library and the Internet, to increase their knowledge (34). The worldwide spread of COVID-19 and the problems in controlling the disease caused by this virus, in addition to creating fear in the masses, has made people with underlying diseases and their families more desperate than other sections of society. The participants of the present study were faced with the fear of referring to medical centers. The current

situation requires the application of some measures by the caregivers of these patients. To manage this problem, Mohammadzadeh *et al* recommended the use of virtual and electronic services. Furthermore, through virtual education of COVID-19 prevention strategies, patients' worries about the limited access to a specialist can be resolved (35). Evidence from other accidents and pandemics also indicated that the outcomes of diabetic patients worsened during and after these disasters (36).

Conclusion

Based on the results of this study, we found that mothers of children with diabetes had different challenges in managing their children's disease, and the coincidence of their children's disease with the outbreak of the COVID-19 pandemic added more pressure on them. The emergence of the COVID-19 pandemic has reduced the mother and child's social interactions with other peers, and the restrictions on social distancing observance and fear of children developing COVID-19 have disrupted blood sugar regulation in diabetic children. Therefore, recognizing the symptoms of blood sugar changes and having the necessary facilities to regulate blood sugar levels are the main steps in accepting the caring role. In addition, the existence of a virtual communication channel between the families of diabetic children and the treatment team can be effective in managing the disease and reducing the anxiety of these families. Moreover, support of health care systems for education and the establishment of charitable associations for financial support can decrease the burden of these families. On the other hand, easy access to the glucometer, tip test, insulin, syringe, and special needles are essential for managing diabetes. Since the majority of participants in the present study were at a low level of financial status, adequate insurance coverage as well as provision of free or inexpensive facilities for the care of a child with diabetes is inevitable.

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Conflict of Interest

There are no known conflicts of interest for any of the authors of this manuscript that would interfere with the integrity of this research.

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