**ORIGINAL ARTICLE**

**Lived Experiences of Mothers with Diabetic Children from the Transfer of Caring Role**

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**Abstract**

**Background:** Following the confirmed type 1 diabetes in children and their discharge from the hospital, the care responsibilities are transferred from nurses to mothers. These mothers are faced with many challenges to play this caring role. The aim of this study was to explore the experiences of the diabetic children’s mothers from the transfer of caring role.

**Methods:** In 2016, semi-structured interviews with Eleven Iranian mothers of children (aged≤14 year) with type 1 diabetes were conducted. Data were analyzed using Colizzi’s phenomenological method.

**Results:** The following themes emerged in this study: ‘Facing the care management challenges,’ ‘care in the shadow of concern’, and ‘hard life in the impasse of diabetes’.

**Conclusion:** The mothers of children with type 1 diabetes, who undertake the caring role that has been transferred to them by healthcare providers, are faced with many challenges. They feel a lot of concerns and experience a hard life. Thus, understanding the experiences of these mothers by the health professionals, to improve the quality of care, is necessary.

**Keywords:** Child, Mothers, Qualitative research, Type 1 diabetes

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INTRODUCTION

Type 1 diabetes (T1D) is one of the most common chronic diseases in children.1,2 The exact number of patients with T1D around the world is unknown, but it seems that the annual prevalence is rising globally.3,4 The prevalence of diabetes in Iran has increased by 35% over the past seven years.5 In Iran, it has been 15 years since the prevention and control of diabetes have been formally considered as the priorities of healthcare.6 One of the unique characteristics of T1D is its progressive nature and its impact on the lives of the children and their family.7 The whole family is affected by the management of diabetic child. This management requires continuous awareness and poses many challenges for the parents because they do not have any clear image of their role as a care provider.8,9 They are also exposed to numerous potential sources of stress, and the mothers are affected more than the other family members who are at risk of psychological problems.10-13

In several studies, it has been reported that the caring role, effectiveness and compassion of mothers are more important than those of the other family members,8,14-18 and they are considered as the largest group of family caregivers.19 Considerable changes in recent decades regarding the education and employment of Iranian women as well as the expectation to take on complete maternal role have caused Iranian mothers to assume more responsibility for caring their children.20 Also, other studies indicated that controlling the metabolic condition of diabetic children has a close relationship with the level of mothers’ stress; the blood sugar of the children whose mothers had higher levels of stress was less controlled.21-26 Hence, it is important that the healthcare providers support and guide them. These findings highlighted the challenges experienced by these mothers. Therefore, it seems that there are still several unknown qualitative dimensions of the phenomenon by taking into account the cultural, economic, social and religious differences of Iranian mothers of children with T1D.

The understanding of these experiences by health professionals would help them provide more effective services to meet the needs of these mothers. The first author’s experience for caring of diabetic children and facing the problems of these children’s mothers led the research team to explore the experiences of these mothers. This study aimed to explore the experiences of mothers with diabetic children after the transfer of caring role.

MATERIALS AND METHODS

The present study was conducted from March to December 2016, on the basis of the descriptive phenomenological research methods. This enabled a rich understanding of ‘lived experience’ and as a method widely used in the field of qualitative research.27 The bracketing technique was utilized to enhance the study’s trustworthiness. Therefore, prior to the study, the researcher identified assumptions and preconceptions related to the phenomenon. Through this process, its impacts on the study findings are reduced and the data emerged in its pure form.28 The participants in this study consisted of mothers of children with T1D who were regular visitors to the diabetic center in Kerman, Iran. The inclusion criteria included the passage of at least one year from the diagnosis of diabetes in the children, and the maximum age of the children not more than 14 years. Due to the nature of this study, the data are obtained from people who have experience and deep knowledge associated with the desired phenomenon. Thus, it seems one year is suitable for gaining experience in this regard. Exclusion criterion for participation was lack of willingness to participate in the study. Eventually, 11 mothers were selected purposefully with different demographic characteristics (in terms of age, education, and duration of diabetes among children). The interviews setting was determined in coordination with mothers, including home (one), workplace (two), Razi School of Nursing and Midwifery (one), and the Kerman Diabetes Centre (seven). The data were gathered via semi-structured and open-ended
interviews which lasted 45–90 min. Examples of guiding questions was: “When did you first go home from the hospital?” “What was it like to take care of ...?” “What was your feeling about your ability to play your role?” The interviews were audio-recorded and transcribed verbatim. Data collection was stopped when data saturation occurred; that is, when no new findings or themes were identified in any new data collected.

In this study, the 7-stage Colaizzi's method was used to analyze the data. This method allowed the researcher to reflect on and interpret the emerging themes. Therefore, after conducting the interviews and writing the recorded information on paper, the interview transcripts were read carefully to understand the participants’ experiences and deeper concepts (first stage), and then the most important phrases containing rich concepts regarding the experiences of the mothers were extracted (second stage). At the next stage, the meaning of each important phrase was explained, and the meanings were written down and coded (third stage). Then, the codes were organized into categories and compared with the original statements of the participants for validation (fourth stage). After that, the full descriptions of the mothers’ experiences were combined and reviewed to achieve clear and unambiguous concepts (fifth and sixth stages). Finally, the findings were returned to the participants to determine the validity of the results, which were approved by them (seventh stage). Interview transcripts were coded independently by the first author for identification of initial themes and then checked by other authors for inter-rater agreement. The software was not used to analyze the data. To ensure the rigor of the data, Lincoln and Guba’s criteria were used. These included: a) Credibility: a long term interaction was held with the participants and by having a discussion with three of the participants, the initial codes and extracted themes were confirmed; b) Conformability: the author first reviewed the obtained data with one of the researchers, and then the results were compared together; c) Transferability: the researcher provided a detailed description of the inquiry and participants were selected purposively; and d) Dependability: some individuals, who had great expertise regarding the subject, were selected to review the results and discuss them with the participants.

Ethical Considerations
The Ethics Committee of Kerman University of Medical Sciences approved the subject and method of this study with the approval code: ir.kmu.rec.1394.678 and written consent forms were signed by mothers. Also, participation was voluntary, and participants could withdraw from the study at any point without repercussions to their on-going care.

Results
The personal information of the mothers who participated in this study is presented in Table 1. In total, 3123 codes, nine subthemes and three themes of ‘facing the care management challenges’, ‘care in the shadow of concern’, and ‘hard life in the impasse of diabetes’ were extracted from eleven interviews. A summary of the initial codes, subcategories and main categories are presented in Table 2.

1. Facing the Care Management Challenge
With the confirmed diagnosis of T1D in children and their discharge from the hospital, the care of these children was transferred from healthcare providers to mothers. In addition to the maternal role, they had to play a caregiver’s role; consequently, they faced several challenges. Therefore, to play this role effectively, they had to acquire the knowledge and skills. Also, they needed to family support.

1.1. Managing the Care Challenges
The majority of the mothers were confused about received training regarding lifestyle changes, such as managing the children’s diet. The children’s non-cooperation with the
diabetic diet was one of the problems because it was inconsistent with children’s demands, and they couldn’t resist their desires.

‘My child should eat low fat diet, but whatever she sees, she wants to eat. She cannot control herself, and I do not really know what to do’ (M: 11).

‘When I inject his insulin, he needs to eat something, but he does not eat anything and says he is full; I tell him that he can have only one sweet that he likes the most, but he does not listen to me’ (M: 3).

Another responsibility of the mothers after discharge is the management of the children’s blood sugar. Since it is affected by factors such as nutrition and stress and can change quickly, they are forced to check the blood sugar of their children after consumption of each meal in order to calculate the amount of insulin. Consequently, this requires a frequent painful process of blood sugar testing, and the children do not easily comply with it.

‘My child does not relish the process of checking her blood sugar. I must caress her to let me check her blood sugar, but sometimes I have to do it by force’ (M: 2).

The successful management of this disease requires the complete cooperation of the children in all aspects. However, a number of mothers expressed their concern that since this disease had started in childhood, and they did not understand it, they are often faced with children’s resistance.

‘If I forget to inject his insulin, he does not remind me. Sometimes, he says he has injected his insulin, but, in fact, he hasn’t because it is painful’. (M: 8).

1.2. Sharing the Burden of Care

Almost half of the participants told that to meet the high cost of treatment for their diabetic children, they had to work. This caused them to stay away from home and their children for a long time, so they needed the
In the face of various challenges, mothers required the support and partnership of others. ‘I have to work to meet the costs. When I am at work, I ask my mom for helping me to take care for my child’ (M: 11).

A number of mothers stated that the administration of a painful procedure like the insulin injection was very painful for them, and that’s why they resorted to others to carry it out.

‘The first time I wanted to inject insulin, my hands were shaking. I was so upset that I could not do it, so I asked my brother to inject the insulin’ (M: 6).

Due to numerous roles and complications in child care management, the mothers required the help of their husbands. The majority of the mothers stated that their husbands had participated side by side in the care and management of their children.

‘My husband goes to the Diabetes Association; he has become a member of different associations and gets books to read’ (M: 3).

Some mothers expressed that their family and friends did not support them adequately in caring for their children because they thought that caring for a diabetic child was difficult and may anytime create unpredictable conditions for the child, which would be impossible to control.

‘Nobody is willing to accept him for a day. They say they are afraid. If his blood sugar goes up or down, they cannot calculate his insulin unit’ (M: 7).

### 1.3. Trying to Acquire Knowledge and Skills

The majority of them said that they had not neglected anything in this regard, and taken...
all opportunities to increase their knowledge, because they felt that there would still be some information that they needed to know. They also needed a trusted source.

‘I regularly go to the Diabetes Association. I need their training programs. I really like to learn everything’ (M: 10).

However, some of the mothers stated that the given information was not enough, and to increase their knowledge, they referred to different resources such as a library and the internet. Some others used the experience of peers to acquire the necessary knowledge.

‘Received trainings were somewhat useful, but I acquired more knowledge by reading books and browsing websites on the internet’ (M: 2).

‘I gathered information by speaking to other mothers. I think that these were more useful for me as I learned more’ (M: 9).

2. Care in the Shadow of Concern

These mothers had been experiencing various emotional stresses such as guilt, obsession and anxiety. It was very difficult for them to manage all their daily duties, so they felt a heavy burden as they had to meet the caring needs of their children as well.

2.1. Remorse for Neglect in Care

Sometimes the children’s management interfered with the mothers’ personal affairs, and this led them to care less for their children. And if something happened to the children in the meanwhile, the mothers suffered from feelings of guilt and blamed themselves.

‘When my child’s blood sugar goes up or down, that is the worst day for me, and I feel that this happened because I was busy with my own affairs’ (M: 11).

The mothers tried to spend most of their time caring for their children, and follow them in all aspects of their lives. Some of them felt that they had made a big mistake if they left their children for a while, because they believed that nobody could manage their children like them.

‘I must be there all the time; I should take care of my child. If I leave her, I feel that it is a big mistake’ (M: 2).

Other mothers faced a feeling of guilt due to inadequate understanding of the initial symptoms of the child’s disease. Some of them admitted that there was no diabetic person in their family, so they did not recognize the symptoms. For some others, the disease was totally unknown. Some of the mothers experienced remorse for giving unhealthy diet to their children previously. They stated that perhaps their children’s diabetes could have been prevented if they had had a better manner.

‘My son is too weak. I always thought that it was nothing, so I delayed the clinic visit because I don’t know the diabetes symptoms’ (M: 5).

‘I must admit that we drank a lot of soda. I feel perhaps that’s the reason that she became diabetic’ (M: 4).

With the confirmed diagnosis of diabetes in children, the mothers faced the acute mental crisis such as consternation, confusion and shock. All their attention was focused on their sick children, so they were not able to focus on other events and issues around them.

‘When someone talked to me, I kept saying, “Let my husband come here and speak with him.” I just kept crying. I had not paid attention to those who had much experience in this regard’ (M: 1).

2.2. Annoying Preoccupation

One of the issues that preoccupied these mothers was the fear of bad event, something that would happen to their child when they are away. The mothers were aware of the potential problems and complications of the disease and they may not be able to control them.

‘When my child is not next to me, I feel stressed; I am afraid that something bad might happen to my child and nobody would be able to do anything’ (M: 1).

‘Taking advantage of new treatments was important for mothers because they believed that lifelong treatment with insulin injections and its management were very hard. They felt that if they got access to new treatments,
their children would be relieved from pain and discomfort.

‘Once a woman said, “Have you heard that there is a device that gets placed in the abdomen and administers insulin automatically?” ’ I think that such thing would be good for the kids as it would prevent insulin injections’ (M: 10).

2.3. Concern about the Child’s Vague Future

Owing to the impact of diabetes on various aspects of children’s lives, the mothers experienced a life full of concerns, knowing that diabetes was a threat to children’s health and its complications may affect them later. These mothers were obsessed with presumptions of a vague and uncertain future for their children.

‘I am always thinking about his future. I wonder what will happen to his body. Can he be successful in his life? I do not know; the future is unclear’ (M: 3).

Another area of concern for these mothers was the possibility of their children’s marriage. They think whether their children with diabetic complications could get married, and whether or not the community would accept these children? The mothers were very disturbed by this mental obsession.

‘It's so hard for a girl, especially in our society. When she wants to get married, will anyone be interested in her? These issues worry me about my child’s future’ (M: 4).

3. Hard Life in the Impasse of Diabetes

The use of specialized services for these children is very expensive. The insurance coverage for medicines and other requirements is not enough, and to meet these needs, the families have to engage in the complexity of the organizations’ bureaucracy. These problems cause the mothers to feel that they are on a warpath, and are forced to take full-time jobs outside home against their will in order to cover these costs.

3.1. Facing Financial Difficulties

The costs of lifelong treatment with insulin, continuous control of blood sugar, and requirements for the management of children’s care along with special diabetes diet are very difficult for these families, especially those with low incomes. This imposes a heavy financial burden on them in such a way that they often have to cut down other family expenses to cover the treatment cost.

‘The test strip and the insulin needle are too expensive. We did not have such costs earlier; but now, we have to save by cutting down on family expenses for the sake of our child’ (M: 7).

Several of the participants expressed that they really liked to use specialized services such as consulting services to improve their children’s health, but owing to the high costs of these services and low household incomes, paying for them was very difficult and sometimes even impossible for some of them.

‘If I had enough money, I would take my child to a psychological consultant once a week. But I can't do so anymore’ (M: 6).

Several participants stated that the income of their husbands was not enough to cover their living costs. Although some of them prefer to spend their time in taking care of their children, others had to work full-time outside home.

‘All of my problems are due to the lack of enough income. That’s why; I have to work all the time. If I do not work, I cannot run my life, and I’ll have more problems’ (M: 9).

3.2. Facing Organizational Problems

Another problem that made the mothers’ life hard was the conflict with organizational problems. They expressed that the support of insurance companies to meet the needs of diabetic children was not enough, and because of the high costs of specialized services in the private sector, they had to go to state organizations. However, even in state organizations, the services were not free.

‘Diabetes centers do not provide any free services. Their services are slightly cheaper than those in the private centers’. (M: 5).

The insulin share was the same for all
children, and some mothers complained that their insulin share did not meet the child’s needs adequately, so they had to buy extra insulin from the free market. Providing for treatment requirements was also difficult for them. Although the insurance companies covered the cost of insulin to some extent, they did not cover some other requirements such as test strips and insulin needles.

‘The insurance companies only pay for four insulin pens, and we have to buy four of them from the free market’ (M: 8).

“The test strips are so expensive and cost even more than his medications. No companies support us and say that these are not free’ (M: 7).

3.3. Facing Diabetes Complications

Facing the complications of diabetes made mothers’ life hard. The incidence of complications in the child, such as confronting the child’s health threatening symptoms and hospitalization in special care units placed the mother in bad conditions. A number of participants said that despite all efforts to control the blood sugar of their children, they are sometimes faced with diabetic complications.

‘She had nausea, and was not able to stay on her feet. She had lost consciousness when we reached the hospital. Her blood sugar was 600. She was transferred to the ICU. It was very hard’ (M: 4).

DISCUSSION

The findings of this study revealed that after the confirmed diagnosis of T1D in children and their discharge from the hospital, the mothers of these children experience several problems such as ‘facing the care management challenge’ ‘care in the shadow of concern’, and ‘hard life in the impasse of diabetes’. Due to the complexity of managing this disease, it is very difficult for the mothers after they take on the role of the caregiver. It’s also frightening for the diabetic children, most of whom put up some resistance against the situation, and thereby makes it even harder for their mothers. The results obtained in this study are similar to those in other studies. Therefore, identifying the needs and problems of these mothers regarding the transfer of the caregiver’s role as well as their education and training by healthcare providers can help them to effectively facilitate the management of this transition.

The demand on a mother after taking on the caring role, especially when she is either employed or forced to work in order to cover the treatment costs of her sick child, is significantly more than that of her daily maternal duties, and so she requires the support of others to share the burden of care. In this regard, their husbands have a vital role to play. Although several studies have shown that the effectiveness, compassion and involvement of mothers were more than the other family members, the statements made by the participants in the study revealed that Iranian fathers along with their wives also participated in the care and management of their diabetic children, and the mothers clearly expressed their satisfaction for their husbands’ support. It seems that this is due to cultural and religious factors, because Islam advises people to help and support their spouses, and this has been repeatedly emphasized as it is considered a moral virtue. In a similar study conducted in Iran, the mothers were also satisfied with the contribution of their husbands, and stated that it brought a sense of peace to them. Mothers sometimes did not receive enough support from others or their participation in the care process. The others refused to participate in caring for a diabetic child because his or her management was scary and difficult, especially in critical situations, and this is consistent with the results of some previous studies. Therefore, it is recommended that centers should be created for the care of diabetic children to be run and managed by experienced nurses so as to provide some relief to the mothers of these children So that whenever these mothers need help, they can use the services of these centers. Confidently injecting insulin during
the initial days of the children’s discharge from hospital had a significant effect on the mental state of these mothers, and it seemed they were not adequately prepared for the experience; therefore, they sought help from the people around them. These results are consistent with those of other studies. In their study to solve such problems, Rankin et al. recommended that nurses should be trained to provide services at home to help these mothers to manage the affairs of their diabetic children, especially during the initial days after discharge, and the mothers should also get support and help with their daily duties through counselling over the phone. The mothers of diabetic children also tried to gain the required knowledge and information regarding services and support networks through personal studies. But sometimes this information was not enough or even not reliable. Thus, they looked for more comprehensive and reliable sources of information. This result was also observed in other studies. Therefore, nurses as the main healthcare providers must identify the unique needs of each mother and provide them with the required support and training.

Usually, the diagnosis of T1D is delayed due to its non-classical symptoms unless there is the occurrence of serious symptoms such as diabetic ketoacidosis. The results of this study showed that the mothers couldn’t detect diabetes in their children by their symptoms. This caused them to feel that their negligence in the care of their children has made them sick, so they blamed themselves. On the other hand, to avoid and prevent diabetes complications, the mothers think they should spend their entire time caring for their children; otherwise, they are beset with self-blame and remorse. Similar feelings have also been expressed by mothers participating in previous studies. With the confirmed diagnosis of a child’s illness, the full attention of the mother is focused on the child’s health status, and she pays much less attention to other issues and events around her, whereas it would be helpful if she uses the experience of mothers who have been going through a similar situation for a longer period of time. The participants in a study stated that notwithstanding their low-down feeling, they took advantage of the opportunities to talk to other mothers of children with T1D and they benefited from using their experiences. It seems that nurses can support these mothers in such situations, and encourage them to use the experience of their peers. One can also design and develop a website or virtual group to provide opportunities for interacting and sharing experiences related to diabetes, and encourage mothers to join the forum.

Awareness of the diabetes complications and its impact on different aspects of child health has caused these mothers to become anxious. Previous studies in similar lines have also revealed such concerns among their participating mothers. The difficulties associated with the available treatment regimens, including insulin injections, have preoccupied the mothers, and they wondered whether the use of new therapies was possible or would the treatment become developed enough to cause less pain and distress to their children. Such a feeling expressed by the mothers in this study has not been observed in other studies. In order to reduce these concerns, nurses could introduce new treatment methods and centers that provide such services to the mothers of diabetic children. The unpredictable health status of diabetic children and the occurrence of acute and critical conditions evoked the prediction of a vague future for their children in the minds of these mothers. Therefore, by creating family-centered care models, nurses can pay attention to the needs of these mothers, in addition to managing their children’s conditions. In another study, family-centered care and parents’ participation and empowerment were emphasized, and it was considered as one of the core concepts of pediatric nursing. They believed this was necessary to maintain the family integrity as well as provide unique
Another concern of the mothers was the inappropriate attitude and view of the community towards their children’s condition because they felt that this issue would affect the future prospects of the marriage of their children. Similar results have been reported by previous studies, especially in the case of female children. Therefore, healthcare providers can take effective steps by raising awareness and improving public attitudes.

The lack of free healthcare services as well as inadequate insurance coverage for insulin and other therapeutic essentials imposed a heavy financial burden on the families of children suffering from diabetes notwithstanding the fact that more than 90% of Iranians are covered by at least one type of health insurance. According to the study participants, it seemed that the available insurance coverage was not enough for the medical requirements of these children. The results of other studies have also shown that the cost imposed on these families was disabling, and they also revealed that even families with higher economic and social status also complained of financial pressures. The results of other studies have shown that the problems pertaining to insurance coverage and finances related to the management of diabetes were more dramatic in developing countries. In several earlier studies, similar results were obtained. Therefore, it is recommended that nurses should identify these families and refer them to charity organizations; the revision of insurance coverage can effectively help to reduce the financial pressures on these families. Facing the complications of diabetes was another issue that had made life hard and unbearable for the mothers in this study. Such experiences were also expressed by the participants in other studies. Since the reduction of these complications requires a careful management of children, the nurses can help these mothers to make decisions about their daily affairs by empowering and identifying their abilities as the first managers of their sick children, and provide training programs tailored to the lifestyle of these mothers.

The findings of this study may have limited generalizability because of the small sample size, geographical location, and unique context. Also, the time duration after the diagnosis ranges from one to eight years and this could be considered as a potential for recollection bias as memories can be impacted by the passage of time. The present study provided unique insights derived directly from the mothers with diabetic children and the findings added to a body of knowledge about experiences of transfer of caring role in a population previously unexplored in this context.

CONCLUSION

The results showed that the mothers of children with (T1D) are faced with several challenges to play the caring role and experience many worries and difficulties. Therefore, by identifying these experiences, health professionals can provide a unique and flexible program based on their lifestyle and teach necessary strategies to effectively manage their life and undertake a caring role beyond hospital walls as well.

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