

ORIGINAL ARTICLE**Mothers' Experiences of Maze Path of Type 1 Diabetes Diagnosis in Children****Maryam Khandan¹, Batool Tirgari^{1*}, Farokh Abazari¹, Mohammad Ali Cheraghi²****OPEN ACCESS**

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ABSTRACT

BACKGROUND: Incidence of diabetes Type 1 in children with non-classic symptoms is one of the reasons for the delay in their follow-up. Failure in its diagnosis by the health professional exposes the mothers to many challenges. This study was conducted to explore mothers' experiences in the diagnosis pathway of diabetes Type 1 in children.

METHODS: Semi-structured qualitative interviews were conducted with fifteen mothers of children with Type 1 diabetes. They were selected by the purposeful sampling method. Their child had a medical file in diabetes centers in Kerman, Iran, at least one year has passed of diabetes diagnosis in their child and the maximum age of the child is 14 years. Data were analyzed using content analysis. Three themes and nine sub-themes emerged during data analysis.

RESULTS: The extracted themes included "presence in the maze path to the child's disease", "facing the reality of the child's disease", and "to grin and bear with new conditions".

CONCLUSIONS: According to the finding, these mothers experienced various challenges. Therefore, identification of these challenges by health professionals to prevent and decrease of them, is necessary.

KEYWORDS: Mothers, Child, Diagnosis, Type 1 diabetes, Qualitative research

INTRODUCTION

Incidence and prevalence of Type 1 diabetes (T1DM) is increasing in the world (1). The prevalence of this disease also increased in Iran (2,3). The disease usually occurs during childhood, and diagnosis of this disease is delayed by health professionals (4,5). Often, there is also delay in following-up the children's health status by parents (6). Recently, guidelines and activities have been created with the aim of raising awareness of the symptoms of T1DM, but there is still not a way to prevent or stop it, and strategies are not useful for early diagnosis (7). The Iranian National Diabetes Committee has started the plans for prevention and control of diabetes since 1999, (8), and studies have also been conducted on screening and early diagnosis of patients with diabetes although their focus is on Type 2 diabetes

(9,10). Therefore, to recognize the problems of these mothers and their children in order to improve the quality of services, more studies are needed.

In a study, parents reported non-specific complaints to the child's pediatrician, but their children's conditions were either not taken seriously and was blamed for lack of experience. It caused the parents to feel fear and doubt, and these conflicts made the management and adaptation of the created conditions more difficult (5). Unexpected diagnosis of diabetes in children changed parents' lifestyle. It caused that they experienced emotional challenges (11). In another study, it was found that the causes of the mothers' reactions at the time of confirmation of the children's disease were sudden diagnosis of the disease, lack of information and lack of enough time to accept the disease (12). These feelings not only take a toll on their psychological state but also indirectly affect the health of the sick child (13). Thus, identification of these feelings by health professionals and helping family members to cope with the new conditions can indirectly affect the health of the child.

Some of these children, at the time of diagnosis, should be hospitalized to regulate blood glucose levels; their parents felt that they had no choice in the matter, while, at this time, they needed training, support, sympathy and understanding by health professionals for coping with the new situation (14). Several studies reported that the mothers are the main family caregivers of children with T1DM, and they are more likely to be affected than other family members. In other studies it was found that there was a direct relationship between the mothers' mental health and the physical health of the sick children (15-20). Hence, these findings showed that these mothers experienced numerous challenges. Therefore, understanding these experiences by health professionals due to the cultural, economic, social and religious differences of Iranian mothers would provide more useful services to them. Therefore, this study was conducted to explore mothers' experiences in the maze path to the diagnosis of children's disease.

MATERIALS AND METHODS

Design and participants: This study is a conventional content analysis of mothers' experiences with a child with diabetes from diagnosis path (21) that was conducted from February 2016 to June 2017. In this method, written, spoken or visual messages have been analyzed and described by a systematic and purposeful method. This method allows the researcher to explore the issues considered in order to further understand them. In the conventional content analysis, raw data is summarized based on inference and interpretation and placed into sub- and main categories. Participants in this study included mothers with children (aged ≤ 14 years) who suffered from T1DM. They had medical files in diabetes centers in Kerman, Iran, and at least one year had passed since diabetes was detected in their children. The exclusion criterion for participation was lack of willingness to participate in the study. Purposive sampling was used to ensure diversity of mothers' age, education, duration of suffering from diabetes. Finally, 15 mothers who wanted to participate in this study were selected after signing a written informed consent.

Data collection: Data were collected using semi-structured interviews conducted by the first author with open-ended questions in order to facilitate the extraction of a wider range of responses from participants. The interview location was chosen in cooperation with the mothers. All interviews were audio-recorded, and all the verbal and non-verbal expressions were then transcribed. Examples of guiding questions were: 1) Describe your experience when you noticed the changes in child's health status, and 2) Discuss your experience of differential diagnosis and ineffective treatments. Also, during the interviews, the participants were asked to describe their feeling when they faced the reality of the child's disease. The Persian language was used for all interviews. The interview time was 65 minutes on average.

Data analysis: Griesheim and Landman's qualitative content analysis method was used to

analyze data (22). In this method, the researcher is an interpreter who has explored data to find the meaningful units. After finding them, he/she performs coding, classification and organizes the data. This process continues until the meaningful categories communicate with each other and the main categories appear (22,23). Content analysis can be performed with different degrees of interpretation. In each text, there are manifest messages vs. latent messages although both messages need interpretations which may vary in-depth and level of abstraction (22,24). Therefore, in this study, it was tried to analyze the latent content as well as manifest contents. In the first step of data analysis, the units of analysis were specified and whole texts of each interview were considered as the unit of analysis. After that, meaning units were identified and they were phrases derived from statements of participants in relation to various aspects of the main concept. Then, coding was carried out, and meaning units were compressed and converted into codes. Codes were summarized and categorized and categories created. Finally, the categories formed the main categories according to similarities and differences. Interview transcripts were coded independently by the first author for identification of initial themes and then checked by other authors for inter-rater agreement. To ensure the rigor of the data, Lincoln and Guba's (1985) criteria were used (25). Prolonged engagement with participants was carried out by the first author to provide dependability and the initial codes, as well as main categories extracted, were confirmed through discussion with three participants. Member check was performed with six mothers to achieve credibility. Sampling technique with maximum variation was used to increase transferability and conformability, which was provided by rechecking the findings with two other faculty members.

Ethical considerations: Approval of the Ethical Committee of Kerman University of Medical Sciences was obtained with the code "ir.kmu.rec.1394.678".

RESULTS

The demographic information of the mothers who participated in this study is presented in Table 1. From the analysis of participants' interviews, three themes of "entanglement in the maze path of the disease diagnosis", "facing the reality of the child's disease and "to grin and bear with new conditions" were extracted (Table 2).

Table 1: Demographic information of the participants (N=15).

Variable	
Mother's age (years)	Median (range) 36(25-48)
Education:	N(%)
Under diploma	3(20)
Diploma	6(40)
BSc	4(26.7)
MSc	2(13.3)
Employment status:	N(%)
Housewife	7(46.7)
Employed outside home	8(53.3)
Marital status:	N(%)
Living with spouse	13(86.7)
Divorced	1(6.65)
Living apart from spouse	1(6.65)
Number of children	Range(n) (1-4)
Current age of the child(year)	median(range) 11(7-14)
Gender of the child	N(%)
Female	6(40)
Male	9(60)
Duration of child's diagnosis (years)	median(range) 4(1-7)

Table 2: Overview of the themes and sub-themes

Themes	Sub-themes
Entanglement in the maze path of the disease diagnosis	Mother attention to non-classic symptoms Attributing child's symptoms to different conditions Facing ineffective diagnosis and treatment Distrust to diagnostic and therapeutic methods
Facing the reality of the child's disease	Presence in critical condition Initial reactions after confirmed diagnosis of T1DM Seeking to find the culprit
To grin and bear with new conditions	Involvement with the emotional challenges Facing various reactions of others Surrender of inevitable destiny

Entanglement in the maze path of the disease diagnosis: Non-specific symptoms of T1DM and mothers' lack of awareness of them, in the beginning, caused confusion. The mothers tried to find the cause of these symptoms. During this time, they encountered diverse problems such as differential diagnosis and ineffective treatment. Because of the lack of child recovery, mothers did not trust physicians' diagnosis. They had to repeat the tests or change the doctor, and it seems that the mothers were faced with a maze path to have their children's disease diagnosed.

Mother attention to non-classic symptoms: Results showed that, most of the time, the created changes in the health of a child had been diagnosed by mothers.

However, in a limited number of cases, these changes were interpreted by others. The reason for this is previous familiarity with the disease.

"I realized that my child had severe weight loss, polyuria, and polydipsia. After a month, not even a gram had been added to his weight" (M 11).

"When my mother saw my child's symptoms, she told me 'this kid has a problem and maybe she has diabetes' because my mother has diabetes" (M 4).

Attributing child's symptoms to different conditions: Most mothers stated that due to lack of familiarity with T1DM and its symptoms, they thought that their children had one of the most common childhood diseases, such as urinary infection and parasitic diseases.

"My daughter drank too much water and had enuresis. I thought that she might have a urinary problem" (M 2).

"She had severe weight loss and paleness. After a month, she did not add a kg and then I said maybe she had parasites" (M 6).

Some of these mothers did not take the symptoms of their child seriously due to non-specificity of the symptoms and their failure to follow-up his/her health condition. However, other mothers stated that they were sensitive to the created changes in their child and tried to find the cause of these changes.

"My brother told me 'the baby has become too weak,' I always thought this is not an important thing and so I had delayed it" (M 5).

"When her symptoms intensified, I took her to a doctor because my husband's family had a history of nephrolithiasis" (M 10).

Facing ineffective diagnosis and treatment: Most mothers said that despite revealing symptoms of a child's disease to a doctor, their child's condition had not been diagnosed and was attributed to other diseases. A few of the mothers said that the doctor diagnosed a child's disease after hearing the symptoms and took appropriate steps for treatment.

"We referred to two doctors. They prescribed some reinforcement syrups. Her condition did not improve. Therefore, we took her to another doctor; he said 'your child is nervous'" (M 1).

"When I told the doctor my child's symptoms, he did a diabetes test and his glucose level is 600. He told us to hospitalize our child immediately" (M 5).

Distrust to diagnostic and therapeutic methods: A number of mothers indicated that they visited various doctors due to mistrust of the doctor's diagnosis or the results of tests. A lot of these mothers believed that diabetes occurs only in adults, or these symptoms have emerged due to change in the diet of a child.

"The doctor said his blood sugar is high and you should hospitalize him immediately. I said, maybe it's a mistake. Do children suffer from diabetes" (M 11)?

Facing the reality of the child's disease: Mothers were put in a stressful situation and with the worsening of symptoms of T1DM in their children; they encountered the fact that their child was actually suffering from T1DM. These mothers were in critical condition and experienced various emotional and psychological reactions.

Presence in critical condition: More than half of the mothers stated that due to delay in diagnosis of the child's disease, the child's symptoms became worse and was hospitalized in ICU. These mothers had faced painful treatment and invasive methods, such as taking blood and repeated injections for their child. They were described it as the worst experience that they had in their lifetime. Even their hands shook at the time of recalling these experiences and they were crying.

"She was in a bad condition. I took her to the hospital quickly. Her blood glucose was 500 and she was admitted to the ICU immediately. I was shattered and cried. I never had such a hard time in 30 years of my life" (M 15).

Initial reactions after confirmed diagnosis of T1DM: Many mothers with the confirmed diagnosis of T1DM in children experience a sense of shock and disbelief, and facing this fact was very hard for them. Hence, they could not control their emotions and some of them said they did not accept the treatment of their child by insulin injection. Thus, they requested the doctor that their child would not be hospitalized.

"I was shocked. I felt the world was finished for me. I could not bear the conditions and I did not understand the things that they were telling me" (M. 12).

"I begged that do not hospitalize my child. They started insulin injection for him; I was so upset, I told them to do something that so he does not need insulin" (M7).

Seeking to find the culprit: After the confirmed diagnosis of T1DM in children, people looked for the cause of this disease. A number of them thought the mother to be the culprit due to improper management of the child's food. Another group of mothers stated that even their husbands had the same feeling. That is, these people considered the cause of the child's illness to be negligence by the mother in child care. It made the situation hard to tolerate for the mothers. Some of them believed that the cause of child's disease might have been related to their behavior and regularly blamed them.

"My husband's family says that it is my fault that the child became sick; 'you did not take care', and this also had affected on my husband" (M 8).

"Maybe our lifestyle has affected my child. Perhaps, the arguments that I had with my husband, has led to stress in my child" (M 14).

To grin and bear with new conditions: A child's disease and hospitalization created harsh conditions for mothers. Their tolerance was reduced, and they became very sensitive to the curiosity and reaction of the people. This matter isolated them, but after a while, they felt that they were forced to accept these conditions.

Involvement with the emotional challenges: Many mothers were experiencing a spiritual crisis, especially in the early days, after discharge of the child from the hospital. Trying to manage the problems of a sick child affected all aspects of the mothers' health. Tolerating people's reaction was difficult; even interacting with them became difficult. Mothers' comments show that they lost their will to socialize because of being too busy with their children's affairs. They were experiencing symptoms of depression including

low expectation and becoming irritable and aggressive. They were crying, in despair and lost sleep.

"In the first month, I did not allow anyone into my house. I had concerned, I became gloomy and I did not want to go anywhere" (M 4).

Facing various reactions of others:One of the issues that made the conditions for a number of mothers more difficult was wrong understanding by others about the management of a child's disease. Also, their extreme attention to the child's conditions could be the result of their lack of awareness about T1DM and its treatment. On the other hand, the mother had to bear the reactions of others and face harsh and stressful conditions when others were curious or showed their pity towards the child.

"The people around me did not know that children with T1DM should inject insulin for the lifetime and were saying 'the child still needs insulin injection?' and this made me nervous" (M 9).

On the other hand, a number of mothers were sad due to low attention and lack of support from others. They said that they did not have the material or spiritual support of people around them, and they behaved as if everything was normal. They felt that the sympathy of the people around them had reduced their discomfort.

"Slowly, people visiting became less and sympathies became by telephone. As everyone was busy with their own lives" (M 12).

Surrender to inevitable destiny:A review of mothers' comments showed that with the passage of time, most of them almost accepted their child's illness and considered it a 'divine exam' or 'inevitable destiny' which they had to adapt in order to maintain their health and their families. Some of them felt that surrendering to these conditions was the only solution.

"I did not want to see my child in this condition, I gradually got used to it. What can I do, these are all a divine exam" (M 3).

"In the first few days, coping with this problem was very difficult. Still, I cannot accept this

because when I see my son suffering, I suffer more than him" (M13).

DISCUSSION

This study was conducted to explore the experiences of mothers in the face of the maze in the diagnosis of children with T1DM. Analysis of data from interviews led to the emergence of three main themes: "entanglement in the maze path of the disease diagnosis", "facing the reality of the child's disease", and "to grin and bear with new conditions". The results of this study show that almost all mothers noticed physical and physiological changes in children. These mothers said that they never thought that their children would be diagnosed with diabetes, and that was why they did not follow-up their child's condition. Only one mother said her mother noticed changes because she had diabetes. Such experiences are also seen in other studies (12,26,27). In a study, half of the parents, prior to diagnosis of their children's disease, had awareness and experience about the symptoms of diabetes. This led to faster diagnosis and treatment of their child (20). Therefore, provided training in relation to this disease and its symptoms were not been enough, and wider plans are needed in this regard.

Almost all mothers said that their children's illness started with a series of vague symptoms. More accurate review of their statements showed that there were two types of responses to changes in a child's health. Some of these mothers did not take these symptoms seriously and did not undertake necessary follow-up for further investigation because they felt these symptoms were related to childhood problems. The second group was mothers who were sensitive to changes in a child's health or the emergence of symptoms were worrying. They at the first opportunity took their child to health centers. These results are in harmony with the results of other studies (12,20,26). Rankin et al. also named these experiences as "prompt and delayed pathways to diagnosis" and pointed out that health professionals could support parents better by identifying their emotional needs (26). Results of

other studies also showed that the main reason for the delay in diagnosis was that parents did not report the obvious symptoms of this disease (6, 28). Often, due to non-specificity of child symptoms and similarity of these with common childhood diseases, this disease was undiagnosed and mothers, due to non-recovery of their child, should frequently refer to health centers. They had encountered different diagnostic and therapeutic methods. Some mothers stated that despite their child's symptoms becoming obvious, doctors did not pay attention to the issue. The results of a number of studies support the results of this study (6,20,26-28). A few of these mothers said that their children's disease was diagnosed at the first visit, and early treatment was started for the child. This result corresponds with the results of a study in this field (4). Another result of this study was mistrust of mothers to the diagnosis and test results since they thought that diabetes in children was impossible and so they visited several doctors and laboratories seeking a definitive conclusion. Similar results were seen in limited studies (4,12). Hence, raising awareness in the society helps mothers to observe these vague symptoms and follow-up their child's health quickly. Also, the existence of guidelines in this regard at children's health centers will make the diagnosis faster.

In a study, information and beliefs with regard to Type 2 diabetes were one of the factors that led parents to follow-up their children's health (20).

However, many mothers did not accept the fact that their children had diabetes thinking that their child's disease was something else. Hence, specific guidelines in this area and informing mothers about them will increase the confidence of mothers on health professionals and diagnosis. Thus, unnecessary referrals

can be avoided. The delay in the child treatment due to the lack of attention by mothers or failure to diagnose by doctors leads to DKA. Such results are similar with the results of other studies (26,29). Results of other studies have shown that raising awareness about the nature of diabetes and its symptoms in parents, teachers and providers of healthcare dramatically reduce DKA in children. It has been suggested that screening in health centers of children can raise awareness about this disease

and result in early detection. Guidelines have also been suggested with regard to this (7,30,31). Almost all mothers said that their children's suffering from diabetes was very difficult. They encountered their child's hospitalization in ICU and observed the suffering of their child due to invasive diagnostic and therapeutic procedures. They said that their concentration decreased. Similar findings

were seen in other studies (32-34). Subsequently, sympathy and support along with awareness by health professionals can reduce confusion of these mothers. Statements of the majority of the mothers showed that tolerating the new conditions was very difficult, and they were shocked to be exposed to stressful conditions. They felt that a mistake was made in the diagnosis of their child's disease, and for this reason, they were resistant to starting treatment with insulin for their child. Mothers' experiencing such feelings were identified in other studies (5,12,27). Therefore, health professionals can provide the required guidelines by identifying the training needs of these mothers and encouraging them to cooperate.

Some mothers said that their families did not know the reality of T1DM. Thus, they felt that the mother is the culprit of child illness. Even their husbands blamed them, and this made it more difficult for mothers to cope. In other studies, these mothers, as the result of ignorance, were blamed for their children's disease (27,32,35). Therefore, one of the tasks of health professionals is raising awareness among all family members with regard to the nature of T1DM in order to reduce additional pressure on mothers.

These mothers said that they feel social isolation, dejection, despair and low expectations. They cried, became irritable and experienced sleep impairment as well as severe grief. There are similar results in other studies (5,11,12). Since it was shown in several studies that the quality of mental health of a mother has a close relationship with the health of a child with diabetes and the management of children (18,19,34,36), identifying the problems of these mothers and giving them support can indirectly affect the child's health. It also helps mothers manage their child better. Another problem of these mothers was people's

different reactions and their poor understanding. A number of mothers were sad because of insufficient support and sympathy from the people while other mothers were tormented by extreme attention and reactions. However, most of the mothers said that support and sympathy of from others reduced their discomfort. In other studies, mothers saw that people failed to understand the nature of diabetes, treatment options and care; it led to inadequate support(5,37,38). Hence, identifying this disease and its treatment methods for people and emphasizing reasonable support by people around them can reduce the emotional pressure on mothers.

After stabilizing the child's condition, mothers felt that it was time to cope with the new conditions. A group of mothers considered their children's condition a divine exam that should better be accepted with the hope that God would give remedy.

However, others felt that it is inevitable condition to which they had no choice but surrender. A similar result is also seen in another Iranian study(12). While the results of another study showed that, over time, most parents control the new conditions by caring for the child in a sympathetic way and creating flexibility in childcare. They try to cope with the conditions by focusing on their children's achievements(35). It seems that the reason for these differences was

The cultural and religious diversities among Iranian mothers and these mothers. Therefore, Iranian mothers acquiring adaption skills have greater ability to solve problems. Hence, the existence of support systems to identify and teach these mothers on coping skills are necessary.

The results showed that mothers of children with T1DM experienced tremendous confusion from appearance of early signs of the disease appeared until its confirmation through diagnosis, for which they had to bear emotional and psychological stress. If this disease is diagnosed late, the mothers get more nervous. Thus, it is suggested that guidelines be designed for the early diagnosis of T1DM and vague symptoms reported by mothers should be considered as a warning sign for the disease. Identifying the

problem and providing comprehensive support, empathy and physiological counseling to these mothers would be one of the most important duties of health professionals. It is also suggested that all the members of the family be trained about the nature and management of this disease. Further research in this area could include investigations of experiences of other family members and healthcare providers.

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