

Mothers' experience of having children with diabetes

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ABSTRACT

Background: Diabetes is a major health problem, which has a wide prevalence in the world. There is no sign of its stopping, but it is increasing. Diabetes in children is three to four times more common than other childhood diseases. Diagnosis of diabetes for children causes emotional responses in parents and family members. Interventions for children with diabetes involve the family, child, and professionals including physicians, nurses, and nutritionist. Self-care is difficult without direct parents' participation. According to studies, burden of diabetes for mothers is more than for fathers. This study aimed to explore mothers' experience of children with diabetes.

Materials and Methods: This is a qualitative content analysis. Study population was recruited through purposeful sampling. Eleven mothers who have a child with diabetes and referring to the "Glands and Metabolism Research Center" and "Al-Zahra Hospital" were selected. Participants were aged 28 to 42 years. Data gathering was done through deep interviews with participants in 2007 that was tape-recorded. Mean average of interviews was 45 minutes. Data analysis was done using conventional qualitative content analysis.

Results: Participants' experience was classified in the two main concepts including reaction at the time of diagnosis and disease consequences for mothers.

Conclusion: Mothers of children with diabetes expressed some reactions at the time of diagnosis, which was mainly due to lack of information, and lack of attention to their needs at the time of diagnosis, especially it was due to the sudden diagnosis and lack of enough opportunities for mothers to accept the disease. The disease causes some consequences for mothers that affect their lives. Therefore, it is necessary to consider the needs of families of children with diabetes and to provide support and sufficient information about their child's illness for them.

Key words: Children, diabetes mellitus, Iran, mothers, qualitative research

INTRODUCTION

Diabetes not only is a prevalent disease, but it is a major health problem, which has a wide prevalence in the world. There is no sign of its stopping, but it is increasing.^[1] Approximately 17 million Americans have diabetes, and this number is expected to rise to 22 million in US by 2025. It is predicted that the number of people with diabetes rise from 135 million in 1995 to 300 million people in 2025 in the world. Vascular complications of diabetes increase myocardial infarction, stroke, kidney failure, blindness, and amputation.^[2] Iran also has the same situation. Three million people had diabetes in 1377. It is predicted to be more than three times during the next 25 years.^[3] Diabetes in children is three to four times more common than other childhood diseases.^[4] Diagnosis of

diabetes for children causes emotional responses in parents and family members. Physiological and psychological effects of diabetes on the patient and family lead to profound changes in their lifestyle. Therefore, it can make a crisis and imbalance in the family, and increase patient and family's stress.^[5] Diabetes is not curable but is manageable and is mainly influenced by daily self-care.^[6] Interventions for children with diabetes involve the family, child, and professionals including physicians, nurses, and nutritionist.^[7] Self-care is difficult without direct parents' participation.^[2] According to studies, burden of diabetes for mothers is more than for fathers.^[8] Although scientific and clinical research have shown numerous effects on the families,^[5] disease is a unique experience for each patient. Unpredictable, acute, and chronic findings create meaningful experience for patient. These experiences are meaningful when the disease disturbs family life and social interaction.^[9] It is important to understand caregivers' experience to provide appropriate care to children. Successful management of caregiver and patient requires a comprehensive understanding of factors affecting caregivers' experience and their support.^[10] In this regard, Lowes *et al.* (2004) conducted the research to explore parents' experience of caring of diabetic children in their first year of diagnosis. Twenty parents of diabetic

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children who were cared at home at the time of diagnosis were interviewed. The results of their study showed that many parents had been frightened and feared. Providing adequate and timely information was important for all parents. They were satisfied with home care. Home care helped parents to do diabetes-related interventions along with their daily life activities. Parents expressed that if they could lead a normal life, their diabetes could not be overcome.^[11] There is emphasizing on the importance of parents' experience and its effects on the life process and follow-up. In addition, it is important for nurses to understand parents' experience for care planning. Given the above-mentioned issues, lack of studies in this field in Iran, high prevalence of the disease, and the role of mothers in the care of diabetic children, this study aimed to explore mothers' experience of children with diabetes.

MATERIALS AND METHODS

Nowadays, researchers use qualitative methods to discover personal behavior, feelings and experiences, and the essence of human life.^[12] This is a qualitative content analysis. Study population was mothers of children with diabetes referring to the "Glands and Metabolism Research Center" and "Al-Zahra Hospital." Inclusion criteria were having a diabetic child confirmed by an endocrinologist, recently diagnosis of diabetes (less than 1 year), ability to participate in the interview and verbal transmission of information and their experiences, willingness to participate in research, having motivation and co-operation for interview, and having a major role in childcare. Research environment was Al-Zahra Hospital, and Glands and Metabolism Research Center to where children with diabetes and their mothers refer. Selection was based on this fact that most patients with diabetes around the city are referred to the endocrine research center, and thus, it provides the maximum possible sampling variation (i.e. cultural, social, and economic variation). Al-Zahra hospital provides access to samples with the wide variety of clients. Researcher recruited samples after obtaining an official reference and permission from medical university and study environment. Interviews were conducted in those centers with participants consent due to convenience. Purposeful sampling method^[13] was used to select participants who had rich information about the phenomenon. Researcher attended the research environment and selected study participants according to the inclusion criteria. Each participant was interviewed after explaining study goals and obtaining informed consent. Since qualitative research focus mostly on data obtained from events rather than sample size^[13] and sampling will be continued until saturation,^[14] in this study, saturation was achieved with 11 interviews, so that no new data was obtained.

Data collection was done through depth interviews. Participants were encouraged to describe, "How was diabetes diagnosed for their child" and "what did they experience at that time." In response to these questions, they described their experiences in this field. Participants' comfort and quiet environment was considered during the interview. Mean average of interviews was 45 minutes. In this study, the researcher tried to avoid carefully any bias in the data-gathering process. Researcher introduced herself thoroughly to the participants, and described accurately study importance, goals, and data-collection method. In addition, participants were ensured about confidentiality, and they were free to quit interview in each point. Finally, participants were informed about extracted contents of the interviews. The individual characteristics of participants in all phases of research were kept completely confidential. The data were analyzed using conventional qualitative content analysis.^[15] Interviews were coded openly after careful several re-reading. For this purpose, the interviews were divided into semantic units, which then were summarized and converted to code. Different codes were compared based on their differences and similarities and were classified to some categories. The categories were compared, and similar categories were merged. Finally, themes were emerged.^[16] Researcher in this study used prolonged engagement, member check, and peer check to increase credibility. For prolonged engagement, long meeting and interviews was done to achieve deep understanding of each participant. The results of each interview were returned to each participant in order to obtain member check. It means that after coding each interview, the researcher returned extracted codes to participants to confirm the data and extracted themes, to ensure about the accuracy of codes and her interpretations, and to correct codes if it is necessary. For peer review, co-researchers reviewed interviews. Co-researchers reviewed data to explore the accuracy of the data analysis process and to ensure confirmability. In addition, all raw data, including tape-recorded interviews and documents, were stored. For transferability, researcher described accurately and purposefully research process and all related activities. After the final extraction, participants checked data, and they confirmed findings.

RESULTS

Eleven mothers of children with diabetes were interviewed at Endocrine Research Center and Al-Zahra Hospital to achieve the research objectives. Participants were aged 28 to 42 years and children aged 4 to 16 years. All participants were married. Five participants had the high school education and higher, five had the diploma or less than, and one was illiterate. Participants' experience was

classified in two central concepts including reaction at the time of diagnosis and disease consequences.

Reaction at the time of diagnosis

Participants' feelings at the time of diagnosis were categorized in six sub-themes including denial, shock, presentiment and concern, anger, anxiety, and impatience and crying.

Denial

Denial was one of the participants' reactions at the time of diagnosis. One participant said about denying the child's disease:

I myself knew that her blood sugar was high, because her grandmother and aunt have diabetes. Yeah, I understand, and I wanted to take her to hospital. However, her father fight me and said, "Why do you say these things, you want to show my kids as a patient." Later, I gave her a little pumpkin to decrease her blood sugar. Then she got sleep.

Another participant said

Her father is much worse than I am. He has not wanted to discuss about this disease. He has been here and has not gone home from last night.

Shock

One of the early responses at the time of diagnosis was shock. One participant in this case said:

The more time passed, I asked, and I knew more. It is hard to digest it psychologically. Diabetes is a disease that comes like a shock. Some diseases come with previous sign, with pain, with discomfort, with illness. However, when your child is healthy, and the only symptom is going frequently to the toilet, it is a shock.

Another participant said

My kid got this disease in three weeks. It was suddenly. I was very shocked. Not only me, but also his father. He is worse than I. I cannot accept it.

Presentiment and concern

Participants experienced anxiety and concern at the time of diabetes diagnosis for their child. One participant stated: Its complications and management is hard, I am not with his at school. He is only a child; he does not know how to behave. I do not know how to inject, sometimes I convince myself and tell myself that some classes would be held for us. However, I cannot accept.

Angry

One of the other participants' reactions at the time of diagnosis was angry. One of the participants in this regard stated:

It is too hard for me. I am asking why my kid? I have never thought that my child have diabetes. I did not think that my 4-year-old kid gets diabetes. I had heard that diabetes can be for adolescence, or had seen it on posters, but I never thought that a 4-year-old child can have diabetes. From last night, my world is dark, and I do not know what to do.

Anxiety

Participants were anxious about their child's diagnosis. One of the participants stated here:

For the first time that I heard that my child has diabetes, I was very anxious, and I shocked.

Impatience

One of the participants' reactions at the time of diagnosis was impatience. One participant said:

First, I did not understand that what diabetes is. After I watched the film, I could understand what it is. I am very upset. First time that insulin was injected for her, I was so upset and cried, but physician talked to me, and now I am more comfort.

Another participant said

I felt that the world was destroyed on my head. A TV program had shown a 4-years-old child with diabetes. I was so upset and sorry for that kid. It is hard for me to digest. When my relatives call me, they cry. I would cry myself when I hear them. I cannot believe it at all.

Disease consequences

Participants' experience about the consequences of diabetes diagnose were categorized in five sub-themes including living with the uncertainty and concern, trust in God and a spiritual connection, false hope, devotion, and divine test.

Living with the uncertainty and concern

Some participants' experience was related to this concept during child's diagnosis and its related care, which was expressed in the different forms. One main reason for uncertainty and concern was due to the responsibility for the care and the lack of confidence. Some participants expressed concern, because they feared that it is possible for them not to provide proper care. One participant said: This disease is not easy. It will not be cured just with one injection. It requires a lifelong insulin injection. I feel that I have a responsibility, and I do not know can I do this.

Another cause of living with uncertainty and concern was high or low blood sugar management. Participants were concerned of possible inability to manage these complications at home. One participant said:

My fear is that when I take him home, maybe his blood sugar decrease at home. I have heard that his blood pressure will decrease, his tooth will be locked, and he will have the cold sweating.

Another participant said

However, I do not want her blood sugar to increase or decrease ... she experience a coma, it is very hard, I scared. I fear when I take home her blood sugar will increase or decrease. I do not know what I should do. When I am here, I am sure that I can rely on hospital. However, I do not know what will happen when I get home.

Other cause of living with uncertainty and concern was future long-term disease complications. Some participants have known patients with diabetes in their family and acquaintances and know about long-term complications of diabetes (due to their job-related information). So, they fear of these complications for their kid.

One participant said here

I know that diabetes affects on the kidneys, eyes. It is very difficult for me. I am nervous. He is so weak. My father had a sore in his toe. He was not cured, and then he died. It was not amputated, but it was not cured until his death. Diabetes affected on his eyes and his kidneys.

Another participants' concern was related to their children's future life. One participant stated:

I thought that my kid would be raised; she wants to get married and wants to have a family, to have a child. These are very effective. These factors are effective. I am worried about her future. I think that every mother is worried. Every mother asks, "If there is an ideal man for my daughter, does she have a problem." I hope that she will be cured and will marry.

Other concern raised by participants' concern was possible lack of proper care during their child's independence. One participant in this case said:

Later, I mean in the future, the child wants to be independent, just wants to be lonely without parents, to go grandma's home, to stay there, to go aunt's house. These situations make me worried. Then again, I told myself, maybe its treatment will come, and so it is not necessary for me to take care.

Another concern was the concern about school attendance. One participant said:

I do not know what will be happen at school when I am not there. He is a child. How should we behave, what should I do with his medicine.

Trust in God and spiritual connection

Other consequence of the diagnosis of child with diabetes was trust in God and the spiritual connection. One participant said:

Then when we took her home, we tried to take care. Then slowly we have the peace through trust in God. God thanks.

False hope

Another psychological consequence of child illness was false hope. One participant said this:

I do not want to accept. I want God to help her cure. I want God and Imams. I want them to show the correct treatment way to physicians and all practitioners. If he does so, they can have more activities, they can try to find treatment, and they would serve the whole community, not only to my kid.

Another participant said

Something in me tells me that your child will be ok. This disease does not remain. She will have a complete cure within 3 to 4 months.

Devotion

Other consequence of the diagnosis was devotion. One participant in this case said:

It is not possible for me to accept a lifelong insulin injection. Why do they say lifelong insulin? I am not convinced, they say that insulin is its cure, I am not convinced; I am ready to transplant of me to my kids.

Divine test

Some participants considered their child's diabetes as a kind of divine test. One participant said:

This is a sort of divine test. From the smallest to the biggest problem, I myself agree that god concluded and advised it for my kid. We can accept that our kid have diabetes. I am comfort, and I convince myself with these things. I can convince myself in this way.

Another participant stated

My soul tells me that my baby will be fine, and this is a divine test.

DISCUSSION

The findings of this study provide an insight about effects of diabetes on the parents' life. Participants' reactions at the time of diabetes diagnosis for their children were denial, shock, presentiment and concern, anger, anxiety, and impatience, and crying. This process is similar to the stages of grief mentioned by Kubler Ross.^[17] In the study, denial was one of the participants' reactions in response to the

diagnosis. After the diagnosis of diabetes for child, mothers did not accept it and did not like to talk about their child's illness at the time of diagnosis. Even some participants suspected of having diabetes, they visited the physician lately due to denial. Other participants' reaction in this study was anxiety. Mothers experienced anxiety and confusion after the diagnosis of diabetes for their child so that they could not accept this diagnosis. Results of Lowes' study showed that most participants experienced anxiety after diagnosis of diabetes for their child. Also, they were unsure about their ability to cope with the children' disease.^[18] One of the other mothers' reactions at the time of diagnosis of diabetes for their child was presentiment and concern. They showed this with their severe impatience at the time of diagnosis. Lowes in her study showed that one of the parents' reactions at the time of diagnosis for their kid was being concerned. Concern was due to changes in life and the necessity of constant care of the child with diabetes.^[18] The results of Wennick's study showed that parents could not speak about their child without crying due to their concerns.^[19] The other mothers' reaction was shock. Shock was due to sudden onset of illness and lack of previous problems in children and due to unexpected disease. That is mothers did not expect for disease. In this respect, the results of Lowes' study showed that parents of children were suffering from shock and distress at the time of diagnosis. Due to the rapid occurrence of events, parents felt that these events are not in their control. Therefore, they were suffering from shock.^[18] Other reaction at the time of diagnosis for their child was anger. Their mothers asked, "Why does my child have diabetes," and showed their anger in this way. As results of Sullivan-Bolayi' study (2003) showed that some parents were very angry after diabetes diagnosis and when they were faced with hypoglycemic periods. This situation was considered difficult.^[20] The results also showed that participants have experienced some consequences due to diagnosis. Consequences of diabetes diagnosis were including living with the uncertainty and concern, trust in God and a spiritual connection, false hope for cure, devotion, and divine test. The results of Mellin's study showed that one of the concerns of parents who have a child with diabetes was occurrence of long-term diabetes complications such as kidney problems for their child.^[21] In Carroll's study, many parents also expressed that one of their concerns was long-term complications due to poor acceptance of treatment regimen by child.^[22] In this study, mothers who were encountered with long-term diabetes complications in their families (such as diabetic foot) or mothers who know about diabetes were more afraid of long-term complications. One of the other participants' concerns in this study was the occurrence of hypoglycemia. Especially mothers, who had faced this problem during the care of their children, experienced severe fear and

anxiety during hypoglycemia. Results of Sullivan-Bolyai's study (2003) showed that occurrence of hypoglycemia and seizure was one of the mothers' problems, so that all mothers fear severely of this situation. Their thought about the need for continuous care for hypoglycemia resulted in sleep deprivation for many parents. Mothers also expressed that another problem is the occurrence of long-term complications, but they felt that their daily practices could reduce long-term effects.^[20] The results of another study by Sullivan-Bolyai (2002) showed that the most important issue for mothers of children with diabetes was the fear of hypoglycemia. In addition, other issues were the future life of child and insulin injection.^[23] One of the other issues that were raised by participants in this study was trust in God and hope. Results of Polzer's study (2007) showed that spirituality was effective in treating patients with type 2 diabetes. Patients' experience about the spirituality was categorized in three groups based on participants' view about the relationship with God. One group of participants believed that God has a supportive or contextual role for them, and both of them (patient and God) are involved equally in self-care. They have faith that God will help people in their self-care. Other group of participants believed that God is stronger than patient. They believed that if they have enough faith, God would heal them. The third group of participants believed that having enough faith, God will heal their diabetes, and for whom faith was a central factor.^[24] The other psychological consequence that was raised by participants was a false hope for recovery. The results of Mellin's study also showed that parents believed that their child will survive and will have a healthy life and hoped for curing their child.^[21]

CONCLUSION

The findings suggest that according to the mothers' reactions and child disease consequences for mothers, families of children with diabetes at the time of diagnosis must be supported and must have opportunity to express their concerns about their child who has diabetes. It is also necessary to provide psychological support and counseling services for families in early stages of the disease, to help them to find a solution for resolving problems. Each family must receive individualized educational issues related to childcare based on their needs. Children and their families must be covered by the diabetes center to be able to use the related services and to receive correct information on how to take care of their children, and to use the call services in emergencies.

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