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A Phenomenological Study on the Lived Experiences of Parents of Children Having Type-I Diabetes with Special Care

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Abstract

Introduction: The purpose of this research was to explore the experiences of parents of children with Type 1 diabetes, focusing on the special care required and the challenges and struggles they face throughout their lifelong journey after the diagnosis. The study also aimed to identify ways to support parents and recognize their remarkable strength and patience.

Methods: A qualitative phenomenological study design was used. Parents (mothers and fathers) of children with Type 1 diabetes who had been diagnosed for at least six months to one year were selected as participants using a non-probability purposive sampling technique. Open-ended, in-depth interviews were conducted to explore the experiences of the parents and how they sought special care for their children with Type 1 diabetes.

Results: Analysis showed that multiple interconnected two themes and within each theme four sub-themes were identified. Two themes are Emotional Journey from Diagnosis Shock to Acceptance, Adaptation and Experiences of Adjusting Lifelong Treatment Journey. Four sub themes were identified such as initial shock, denial, and grief at diagnosis, Gradual acceptance and emotional adaptation, Maintaining Continuous Vigilance" and Being Constantly Alert" at any time.

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Conclusion: Studies have shown that parents often feel emotional stress, shock, and loss of control after their child is diagnosed with Type 1 diabetes. They need to learn many special care skills, such as checking blood glucose levels, giving insulin, managing diet, and identifying signs of high or low blood sugar. Caring for a child with Type 1 diabetes is a lifelong responsibility, and greater awareness in society is also important. The study found that parents feel that caring for a child with Type 1 diabetes is a lifelong process that requires continuous care, attention, and support.

Keywords: Type -I diabetes, parents, experience, children, special care

Introduction

Type 1 Diabetes Mellitus (T1DM) is a chronic autoimmune disease in which the pancreas cannot produce insulin because the insulin-producing beta cells are destroyed (American Diabetes Association, 2023). It is one of the most common chronic diseases among children and adolescents. Children with T1DM require lifelong insulin therapy Proper management of T1DM includes regular monitoring of blood glucose levels, insulin administration, a healthy diet, and lifestyle changes. These measures help to prevent short-term and long-term complications (Chiang et al., 2018).

Special care in Type 1 Diabetes Mellitus involves continuous blood glucose monitoring, insulin administration, dietary management, regulation of physical activity, prevention and management of hypoglycemia and hyperglycemia, and ongoing psychosocial support. Parents play a central role in providing this intensive and lifelong care, which requires constant supervision, decision-making, and adaptation to the child's developmental needs (Streisand & Monaghan, 2014).

Living with diabetes is challenging for children. Poor blood sugar control can lead to acute complications such as hypoglycemia and ketoacidosis. It can also cause poor growth and long-term vascular complications (Patterson et al., 2014).

This role needs constant attention, emotional strength, and a lot of time. Studies show that parents of children with chronic illnesses often experience high levels of stress, anxiety, emotional fatigue, and fear due to daily disease management and possible complications (Whittemore et al., 2012). These challenges become greater when the child needs special care. Qualitative analysis revealed that greater general parenting stress was associated with greater parental responsibility for treatment management and was unrelated to illness duration and severity across illness populations. This increases the risk of caregiver burden and can reduce the parents' quality of life (Cousino & Hazen, 2013).

After a diagnosis is confirmed, Parents felt they needed more emotional support and reassurance after their child was diagnosed with diabetes before receiving detailed information about diabetes care. They wanted health professionals to provide practical help and support that matched their family situation when managing diabetes at home. (Rankin et al., 2014).

Another study showed that Parents described that caring for a child with Type 1 diabetes was stressful and involved continuous responsibility, including monitoring blood glucose,

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managing insulin injections, diet, and physical activity. Parents experienced fear and uncertainty but gradually learned to manage the illness and gained more control through knowledge, experience, and support (Rising Holmström et al., 2018).

This qualitative study explored that parents described fear, worry, uncertainty, and feelings of isolation after diagnosis. They reported challenges in learning diabetes management, adapting family routines, and balancing responsibility for their child's care. The study highlighted the importance of healthcare provider communication, emotional support, and ongoing guidance for families (Smaldone & Ritholz, 2011). Many parents regularly checked their child's blood glucose at night, which was linked with increased worry, stress, and sleep disturbance. The fear of night time hypoglycemia has been reported as extra challenging among parents of the youngest children (Monaghan et al., 2009).

Parents were mainly responsible for their child's daily diabetes care. They regularly checked blood glucose levels (at least four times a day), gave insulin, managed the child's diet by controlling carbohydrates, monitored physical activity, and worked to prevent low and high blood sugar levels. (Silverstein et al., 2005)

This study examined factors that influence parents' feelings of parenting competence. It found that children's behavior, parent characteristics, and family context affect how confident parents feel in their parenting and care giving abilities. (Bogenschneider et al., 1997).

After 6 months to 1 year after diagnosis, parents became more familiar with managing their child's condition. However, they still worried about their child's quality of life and possible future health problems. Although sharing parenting responsibilities with family members is important, many parents found it difficult to decide who should help and how much support was needed. As a result, parents often stayed constantly alert and prepared, which caused ongoing physical and emotional tiredness (Iversen et al., 2018).

Thus, Parents said this time was very stressful and emotionally hard, but they needed more support from health professional (Khandan et al., 2018).

Problem statement

"How do parents of children having Type-I diabetes with special care experience?"

Research Objectives

- To explore the lived experiences of parents of children having Type-I diabetes with special care.
- To explore the emotional experiences of parents caring for children having Type-I diabetes with special care.
- To examine the coping strategies used by parents in special care.

Method and Materials

Research Design

This study used phenomenological research design, specifically Interpretative Phenomenological Analysis (IPA), to explore how parents interpret and give meaning to their parent's experiences. The Study was conducted in Kanti Children Hospital, Maharajgunj. In-

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depth interviews were used as these afforded the flexibility needed for parents to share their own understandings and experiences.

The study participants were parents of children with Type-I diabetes who attended the Outpatient Department (OPD) of Kanti Children's Hospital. Parents of children diagnosed with Type-I diabetes for six months to one year were included in the study because this duration helped to explore their experiences in providing special care to their children. The children's age ranged from 6 to 12 years, which is considered middle childhood. Permission was taken from the parents to contact them again by telephone if needed to clarify information or discuss new issues during data collection and analysis. Participant recruitment continued until no new themes were found. The researchers used purposive sampling technique to select the participants for the study.

Data Collection Procedure

Data was collected after getting ethical approval from IRB National Academy of Medical Science Bir Hospital and IRC Kanti Children Hospital. Verbal and written consent was obtained before open ended in- depth interview by giving 45 to 60 minutes for each participants. Researcher met participants on their follow up day. The researcher introduced herself and explained the aim of the research and took participant's consent for recording their voice. Participants were first identified and interview was taken after meeting with them to gain trust before interview. In-depth unstructured interviews were under taken with parents of children aged 6 to 12 years and under who had been diagnosed with T1D.

The instrument consists of two parts:

Part I: Demographic information of the participant's parents and children

Part II: Unstructured open-ended in-depth interviews

Ethical Considerations

Data were collected after receiving ethical approval from the Institutional Review Board (IRB) of National Academy of Medical Sciences and the Institutional Review Committee (IRC) of Kanti Children's Hospital. Written consent was obtained from both mothers and fathers. Participation in the study was voluntary, and participants were free to withdraw from the study at any time without affecting their ongoing care.

Conceptual Framework Development on the Basis of Finding

Parents had different experiences during the treatment journey of their children with Type-I diabetes and tried to maintain a normal family life. They faced many challenges, including emotional stress and financial difficulties due to the long-term treatment process. Parents also experienced difficulties in managing their children's care, such as monitoring blood glucose levels, managing a diabetic diet, administering insulin injections, and maintaining regular exercise.

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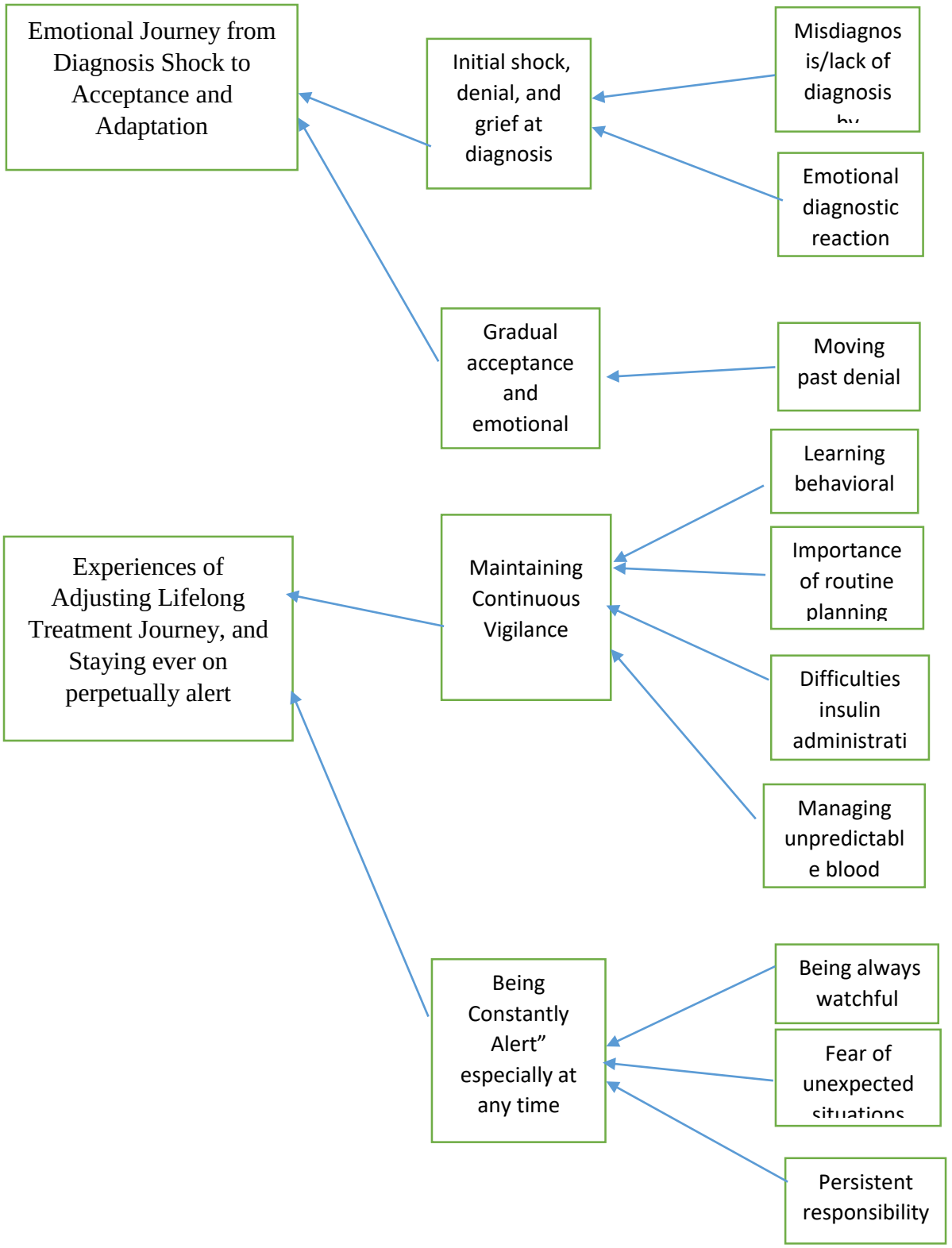

Analysis and Results

Based on the findings of in- depth interviews with participants the similar findings were grouped together from total six hundred six categorized and ten codes into cluster of themes.

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These meetings were also used to develop a series of sub- themes which reflected the topics explored with participants and emergent themes**.**

On the basis of analysis findings are described below Transcript was analyzed using Interpretative Phenomenological Analysis IPA. Make detailed comments about content, language, context, emotions. Researcher may go back and modify earlier steps in the analysis in the light of this feedback. Analysis of data was done side by side. On the same day of interview code number was assigned to information sheet and recorded information instead of personal identity. The recording of the interview was listened repeatedly until the clear meaning is extracted from it. Transcribing was done to create the verbatim at the end of the same day of interview. The entire interview was then translated to English. This method involves finding themes, connections, and patterns in the data. Similar themes are grouped together to form larger themes. IPA is a repeated process where the researcher goes through several steps again and again (Fornasini et al., 2020).

The study findings included many significant statements. These statements were organized into categories by identifying their meanings. Based on the in-depth interviews with the participants, similar findings were grouped together. A total of 606 categories were generated, then organized into codes, sub themes and theme clusters. The findings obtained from the analysis are described below.

The study used the Interpretative Phenomenological Analysis (IPA) approach, which is an iterative and cyclical process where the researcher repeatedly reviews and interprets the data to develop meaningful themes. (Polit & Beck, 2010)

The stages of analysis were:

Stage 1: First encounter with the text

The researcher read and re-read the interview transcripts to become familiar with the participants' experiences and understand the overall meaning of the data.

Stage 2: Preliminary themes identified

Initial themes were identified from significant statements and meaningful sections of the transcripts.

Stage 3: Grouping themes into clusters or concepts

Similar themes were grouped together to form broader theme clusters or concepts that reflected shared experiences among participants**.**

Stage 4: Tabulating themes in a summary table. The final themes and their clusters were organized into a summary table to present the findings in a clear and systematic manner.

Table-1

Sociodemographic Characteristics of Participants n=14

Demographic Characteristics	**Frequency**
Age Group Below 25	**3**
26 to 35	**8**

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Above 36	**3**
Ethnicity	
Brahmin/ Chhetri	**4**
Janajati	**8**
Madeshi	**2**
Educational Status	
Bachelors	**2**
Higher Secondary Level	**7**
Secondary Level	**5**
Occupation	
House maker	**6**
Bussiness /Trekking	**5**
Teacher/Jobholder/Tailoring	**3**
Type of Family	
Nuclear	**10**
Joint	**4**

Table 1 shows that the age of the participants varied from 22 years to 42 years. Regarding the occupation of participants, six of them were house makers, four were business men, one of them did trekking and two of them were a teacher and one of them a jobholder. Participants were four fathers and ten mothers.

Table 2

Socio-demography Characteristics of Children

Demographic Characteristics	Frequency
Age Group	
6-9 Years	**10**
10-12	**4**
Gender	
Male	**8**
Female	**6**
Duration of Diagnosis	
9 months – 5 yrs.	**9**
6 years – 8years	**5**

The children age were 6 years to 12 years. Duration of diagnosis age of children were 9 months to 8 years.

Finding of In- depth Interview

The sample consisted of 14 interviews with parents, ten mothers and four fathers of a child withT1D (aged 6 to12 years). Researcher was able to identify on essential theme across the interviews, consisting of sub-themes code and categories.

Theme: "Emotional Journey from Diagnosis Shock to Acceptance and Adaptation"

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Above theme reflects the new reality parents face raising a child with T1D, beginning at diagnosis and involving changes to daily routines, dietary habits and learning new care giving skills.

Sub theme**: **Initial shock, denial, and grief at diagnosis: parents described the moment of diagnosis as a sudden and overwhelming life event. They were affected emotionally, and financially impact starting at diagnosis.

Codes: Misdiagnosis/lack of diagnosis by professionals Mother tell "Often my child had been misdiagnosed as having cancer, brain tumor or another devastating illness" At that I was shocked and emotionally imbalanced. My child was so precious. What could we do."

One father said, *"I thought it was a urinary infection. I quickly took my child to a doctor for a check-up, but the condition was not properly diagnosed. I was very worried, so I took my child to another hospital based on my friend's advice, where the diagnosis was finally made. My child was found to have high blood sugar." Thank god, my child is surviving"*

Codes: Emotional diagnostic reaction: *mother said that "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. I wept many times."*

With time, parents became used to this new reality and it became part of daily life. Sub theme is explored further below through codes it was derived from: 'distressing diagnostic experience', 'change of life routine' and 'reconstruction of family dynamics.'

T1DM is after diagnosed in childhood, parents initially bear the burden of dealing with their children and helping them understand and manage their condition. In this study, parents expressed distress and had some difficulty in processing their children's lifelong condition given the early age of diagnosis. Administering injection to children also caused parents a lot of suffering:

One mother said, *"It is stressful because it is hard to manage and control a child. When I went to a marriage ceremony, my child wanted to eat everything. At that time, I felt very upset and did not know how to convince him not to eat those foods. He wept and so I left party."*

Sub theme: Gradual acceptance and emotional adaptation

Codes: **Moving past denial**

This adjustment involves reframing expectations for the child's future, reducing emotional distress, and achieving a sense of control and competence in caregiving. Although moments of anxiety and uncertainty may persist, parents increasingly demonstrate emotional resilience, acceptance, and adaptation as they navigate the ongoing challenges of lifelong care.

A mother said, "After my child was admitted to the hospital, I saw many children suffering from type-1 diabetes. While talking with their parents, I realized that I am not alone and that my child is not the only one suffering from this disease. I motivated for coping."

Theme: "Experiences of Adjusting Lifelong Treatment Journey" and Staying ever on perpetually alert

Almost half of the participants believed that being a parent of a child requiring special care is a lifelong journey. Parents learn skill to care child. One parent supported this idea by stating, *"It's a long journey,"* referring to the nature of Type I diabetes treatment.

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Sub theme: "Maintaining Continuous Vigilance"

Codes: Learning behavioral cues

A mother tells, *"I slowly learned how to check my child's blood glucose level. At first, my hands Distressed when I pricked the needle. I wiped when looked the blood, and my child did the same. It was a very difficult situation to cope with."* She also explained that one of the hardest parts of being a parent of a child with special care is communication. Parents need to be adaptable so they can connect with their children and understand their child's needs.

Codes: Importance of routine planning: A mother said, *"Everything happened so suddenly; at that moment, we had no idea about carbohydrate intake. Everything, from how to start, what to do first, and all plans, was completely overwhelming."*

Codes: ***Difficulties insulin administration:*** Another mother and father said, *"Administering insulin feels like a horror; it is like a needle in our hearts each time we do it. However, our dedication also helped us feel better."*

Codes: Managing unpredictable blood glucose readings: The father said, "*My child's blood glucose levels are challenging to predict. For example, during Sangrati, my son ate* chakku, *and his blood glucose level rose very high, making him feel drowsy. Thank God, I was able to manage it properly."*

Sub theme: ***"Being Constantly Alert" especially at any time***

Codes: Being always watchful

The mother said, "I was very sad because I could not leave my child alone. She had fainted and became seriously ill due to diabetic ketoacidosis (DKA), and no one else was there. I brought her to the hospital, and thank God, she survived." She added, "My daughter was repeatedly affected by DKA, and I didn't know why it happened. I immediately brought her to the hospital, and she survived. I am always afraid of these emergencies, especially at any time."

Codes: Fear of unexpected situations

A Father expressed, "My child used to drink a lot, stayed asleep and he complained headache" at that time, I used to give her hot water and gave her sugar" If she did not get well, I used to bring her hospital immediately."

Codes: Persistent responsibility

Father said *"I learnt various activities: how to administer insulin from injections, disinfection, drawing blood from finger om my god terrible condition."* Parents mentioned *"the need for support from family, friends, and health professional" Some parents tell "more time for themselves and wanted to rest more efficiently". One of the participants highlighted that if personal needs are satisfied, there is no need for additional support.*

However, many participants, had a considerable level of support from their immediate families in a variety of ways, including accommodating dietary changes, administering insulin injections, and moral support and encouragement.

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Discussion

This study provided themes into the lived experiences of mothers and fathers of children with Type 1 Diabetes (T1D) requiring special care. It reflected the core findings in accordance with the phenomenological design of the study.

This finding presented in the data are supported by sub theme: Initial shock, denial, and grief at diagnosis

Parents described the moment of diagnosis as a sudden and overwhelming life event. They were affected emotionally, and financially impact starting at diagnosis.

This reflects the study indicating a significant amount of parenting stress amongst parents of children with T1D (Moreira et al., 2014). In addition, the prediction that children with T1D would have higher levels of parent-reported depression and anxiety issues than children without diabetes was also supported.

Emotional condition parents reported that they experienced different emotional as well as psychological problem in their day-to-day life such as they become upset while thinking about their children disease condition, lifelong treatment, and future consequences. So, they expressed frequent wept and misbalance emotion. This finding was supported by Rifshana et al. about that Parents involved attending to emotional responses and managing situations that might cause disruption. They experienced much stress in daily life, practically as well as emotionally, and involving existential concerns. Both mothers and fathers told about a period of denial, grief, and sorrow, which took time to work through, and that was still going on.

This finding presented in the data are supported by sub theme: Being Constantly Alert" especially at night

The mother said, "I was very sad because I could not leave my child alone. She had fainted and became seriously ill at night due to diabetic ketoacidosis (DKA), and no one else was there. I brought her to the hospital, and thank God, she survived." These finding presented in the data are supported by Strider ST that conducted in Africa where parents expressed that the signs and symptoms of a diabetes emergency are easier to identify for a parent with more experience with diabetes management. The common signs and symptoms of a diabetes emergency can vary depending on the child and the circumstances. Hypoglycemia can happen very quickly and if left untreated can cause accidents, injury, coma, and death.

This finding presented in the data are supported by *Rifshana et al., 2017 Facing the care management challenges, a life-changing situation It took quite a long time before the parents experienced that they downed that the situation was changed forever, and it had changed their role as parents. It was hard to accept the reality of their child's long term treatment and they felt overwhelmed by the new situation. This finding also supported by Holmström et al. Finding revealed that parents described how to learn to manage type –I diabetes through observing, learning, and asking questions to the healthcare professionals, but also through the basic education given at the hospital by diabetes nurses and the whole diabetes team (i.e. a professional health care group who work with children and youth with diabetes usually physician, nurse, nutritionist, psychologist.*

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This finding presented in the data are supported by Sub theme: "Maintaining Continuous Vigilance"

Codes: Learning behavioral cues; The majority of parents said that they had not neglected anything in this regard, and taken all opportunities to increase their skill, and knowledge. Parental support in the acquisition of self-care competencies. Parents sharing behavior roles. Similarly, this finding was supported by Rankin et al in University of Edinburgh, UK the study, shows how children understand diabetes and slowly learn to take care of themselves, such as checking blood sugar, taking insulin, and following diet rules with support from parents and health professional.

Codes: Difficulties insulin administration: Another mother and father said, "administering insulin feels like a terrible and feel sorrow each time we do it. Slowly, we feel comfortable to inject insulin." This supported by Kimbell et al., 2021and showed that "Administering insulin feels like a horror; it is like a needle in our hearts each time we do it. However, our dedication also helped us feel better" reflects the emotional burden experienced by parents caring for children with Type 1 diabetes.

Conclusion

The main aim of this study was to explore the lived experiences of parents of children with type I diabetes requiring special care. Parents faced several challenges following the diagnosis. Many parents experienced emotional shock immediately after the diagnosis and gradually adapted over time. They learned essential special caring skills such as insulin administration, blood glucose monitoring, and dietary management to prevent complications such as hypoglycemia and hyperglycemia.

Parents encountered various emotional and financial difficulties in their day-to-day lives. They often felt distressed when thinking about their child's life, disease condition, and future consequences. However, the majority of parents reported receiving strong support from family members and hospital staff.

Therefore, by identifying these experiences, health professionals can design unique and flexible programs personalized to parents' lifestyles and teach necessary knowledge to help them effectively manage daily life and special care responsibilities beyond the hospital setting. These include insulin administration, blood glucose monitoring, and dietary management while caring for their children.

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