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# Lived Experiences of Parents of Children Having Type-I Diabetes Aged 6 to 12 Years

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#### **Abstract**

Type I diabetes is chronic illness which change the life styles of parents, children as well as the entire family. Parents faced many challenges such as care, management (insulin administration, diabetic diet, blood glucose monitoring) and treatment cost. Objective of the study is to explore lived experience of parents of children having type I diabetes. A qualitative phenomenological study design was adopted, and total eleven parents (8 mothers and 3 fathers) were selected as participants by using non probability purposive sampling procedure. Data was gathered by using in-depth interview. The huge information was reduced to smaller statements by grouping similar responses to get actual meaning which were coded, categorized and organized to sub themes and themes. Findings revealed that parents had experienced so many ups and downs emotional feelings during the journey of treatment. They experienced nature of type I diabetes like treatment need for the whole of life, hardship during diagnosis process, facing the diabetes complications, financial crisis and need for treatment in emergency situation. The study also revealed that parents felt permanent impact from their child's previous health condition and disruption of family unit but they were hopeful about their children's future consequences. They struggled for supporting and caring their children's lives at all times in the best possible ways. They learnt to live with children having Type-I diabetes. Parents suggested to launch awareness programs to educate school teachers, staffs and health worker for early diagnosis.

**Keywords:** Type -I diabetes, parents, experience, children



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#### Introduction

When a child diagnosed with a long term illness like type I diabetes the life condition changed for the entire family and increased greater parental responsibility for treatment management unrelated to illness duration and severity of illness (Cho et al.,2017). It was estimated that 98,200 children under 15 years develop type I diabetes (T1D) worldwide annually, with this figure increasing to nearly 128,900 under 20 years. Parents require continuous awareness and face many challenges for management of Type-I diabetes (Patterson et al.,2019).

Polyuria was the most common presenting symptom followed by polydipsia, weight loss and polyphagia. Moreover, most of the children had come in diabetic complication (keto-acidosis) at the time of diagnosis in Nepal (Muktan et al.,2019).

Parents was found difficulty in monitoring blood glucose, in assisting with insulin injections, food intake and physical activity in order to ensure optimum disease management. It could create a sense of burden in the parents' mind, causing stress and anxiety (Rising et al., 2018).

The family could experience strong emotional reactions. Some mothers expressed that their family and friends did not support them in caring for their children because they thought that caring for a diabetic child was difficult and might anytime create unpredictable conditions for the children, which would be impossible to control (Khandan et al.,2018).

The management of type I diabetes of 6 to 12yr age group was found to be challenging as they needed insulin with lunch and most often they were away from home. They needed insulin administration at school. So, proper relationship should be maintained between parents and school personnel for proper management. Taiwan studies showed that parental role was very important to maintain blood glucose level in normal range and encouraged their children for diabetes management independently. Parents also needed to support and assistance from hospital team as well as community members (Rawdon et al., 2019).

Parental lived experience was reported that their daily family practices became disarranged (Strider et al.,2016). So, parents and children had to plan ahead all aspects of family life accommodating diabetes care. Parents needed to reevaluate their lifestyle and adjust routines to accommodate dietary restrictions necessary for their children having type I diabetes (Symons et al.,2015).

This study is important to all health professionals to develop guidelines for unique and flexible program based awareness about Type-I diabetes. The explored themes help to deliver care as well as prominent role for management towards children affected by Type-I diabetes and their parents.

#### **Problem statement**

What are lived experience of parents of children having Type –I diabetes aged 6 to 12 years?



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### **Research Objectives**

- To explore lived experience of parents of children having Type- I diabetes, in tertiary level hospital
- To explore feelings related to nature and effects of type I diabetes on children
- To explore the challenges such as care and management (insulin administration, diabetic diet, blood glucose monitoring) and the cost of treatment faced by the parents in caring for their children of type- I diabetes

#### **Review of Related Literature**

Type-I diabetes is the most common chronic metabolic condition seen in children and adolescents. It is estimated that 98,200 children under 15 years develop Type-I diabetes worldwide annually. It occurred higher rate in 10yrs to 14 yrs. and more affected in male child (Rifshana et al.,2017).

The study was done in Nepal, Dhahran, revealed that polyuria was the most common presenting symptom followed by polydipsia, weight loss and polyphagia. The most of the children had come in diabetic keto-acidosis (DKA) condition at the time of diagnosis. Therefore, community awareness programs should be emphasized among parents and primary health care workers especially in rural areas regarding Type-I diabetes for early recognition and prompt treatment especially in rural areas regarding (Muktan et al., 2019).

Western Norway University of Applied Sciences, Bergen, Norway, study showed that Parents described their experiences that a profoundly changed situation, and they were indeed striving to live like a "normal" family (Iversen et al., 2018). Parents expressed their feeling that they were always on guard. One of the participant(mother) puts it this way:

"Diabetes is an underrated condition; you look healthy— nothing is visible. To be parents in this situation implies that you live in a state of perpetual attention."

This study was done in North, New Zealand, parents experienced that 'Looking after a child with diabetes: Issues of embodiment' Two specific aspects of this main theme, 'Constant vigilance and careful management' and 'Comparing diabetes with other conditions' Study were parents of children aged between 4 and 12 years who had been diagnosed with Type -I diabetes for a minimum of 6 months ((Rifshana et al., 2017).

Walden University in Virginia, USA, study provides insight into population based needs for successful diabetes management, such as how to make healthier cultural and ethnic meals and the need for culturally-centered whole family diabetes education, to enhance family relationships and diabetes management. Parents experiences that the challenges as dietary restrictions, exercising regularly, frequent monitoring of blood glucose levels, and daily insulin administration (Strider et al.,2016).



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#### **Method and Materials**

### Research Design

Qualitative, Phenomenological research design was used to explore the lived experience of parents with Type-I diabetes. Phenomenologist insists on careful description of ordinary conscious experience of everyday life. These "things" include hearing, seeing, believing, feeling remembering, deciding, evaluating, acting and so (Bogdan et al.,1975)..The Phenomenology seeks to gain in-depth understanding of particular phenomena in the life world by giving attention to the experience and perceptions of those who live them through in our case lived experiences of parents with children of Type-I diabetes (Rich et al.,2013).

### Setting of the study

The Study was conducted in Kanti Children Hospital, Maharajgunj. Kanti children hospital is the only government referral tertiary level children hospital in Nepal.

#### The Study Participant

The Study participants were parents of Type-I diabetes children, who were attended in Kanti Children Hospital Out Patient Door. Parents with children of Type-I diabetes diagnosed for at least six months, age 6 to 12 years, were eligible for participation.

Creswell recommended 5-25 participation pool as an appropriate sample size to establish a sufficient account perception, while providing a practical sample size to study the experiences of participants of a phenomenological research study (Mason,2010). Morse suggested that at least six participants needs for the study(Mason,2010). Therefore, eleven participants were selected for the study and reached the data saturation. Non probability purposive sampling technique was used to select the study participants.

#### Data Collection Procedure

Data was collected after getting ethical approval from IRB National Academy of Medical Science Bir Hospital and IRC Kanti Children Hospital. The date and time for the interview was set according to participant's convenience. Verbal and written consent was obtained before starting semi- structured and open ended in- depth interview by giving 40 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.

An open-ended in-depth interview topic guide was developed based on literature review, consulting advisors and subject experts. An audio record of in-depth interview and field notes to record non-verbal clues, the researcher's reflection and the environment was maintained.

The instrument consists of two parts:

Part I: Demographic information of the participants

Part II: A semi- structured open-ended in-depth interview guideline



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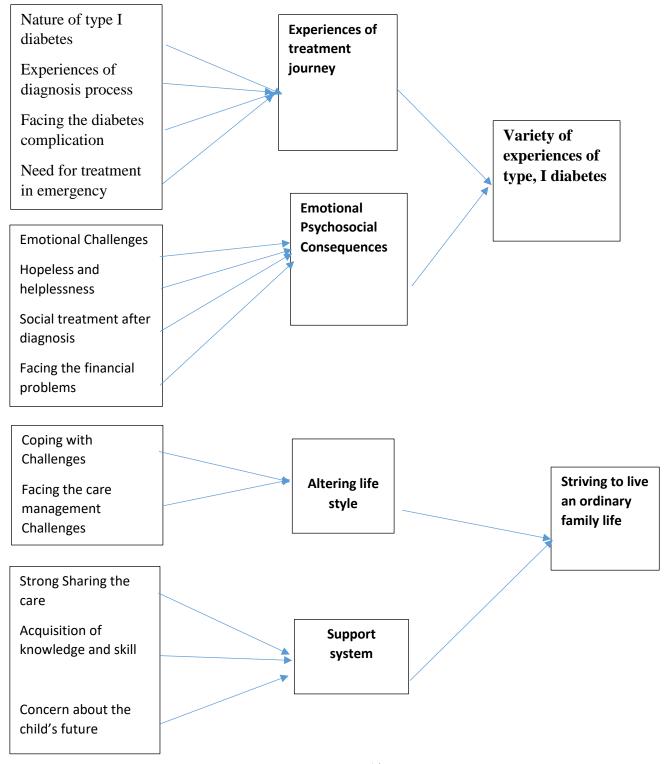
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The study adopted the following framework.

#### **Conceptual Framework**





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#### **Conceptual Framework Development on the Basis of Finding**

Parents felt variety of experience about Type-I diabetes during treatment journey and strive to live normal family life. Parents faced many challenges like emotional disturbances and financial crisis for their long term treatment journey. Parents also faced care management challenges for their children such as blood glucose monitoring, diabetic diet management, injection insulin administration and exercise.

### **Results and Analysis**

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. Transcript was analyzed using Interpretative Phenomenological Analysis IPA. This method involves analysis of tests for themes, connections and concept themes are grouped to from super-ordinated themes. This method adopted by IPA is a cyclical process where the researcher proceeds through several iterative stages (Fomasini et al., 2020).

The result of the study had many significant statements. They were organized into specific of categorization by formulation of meaning. Based on the findings of in- depth interview with participants the similar findings were grouped together from total five hundred fifty- five codes and categorized into cluster of themes. On the basis of analysis findings are described below:

This method adopted by IPA is a cyclical process where the researcher proceeds through several iterative stages (Polit & Beck, 2010).

Stage 1: First encounter with the text

Stage 2: Preliminary themes identified

Stage 3: Grouping themes together as clusters or concepts

Stage 4: Tabulating themes in a summary table

### **Cluster of themes**

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### Analysis of cluster of themes on Parents lived experiences with children of type I diabetes

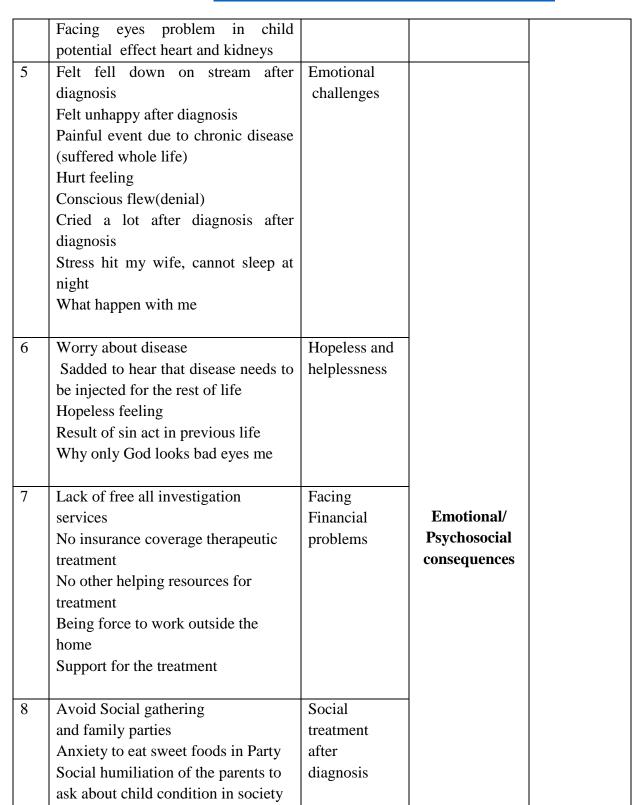
SN	Responses	Categories	Sub-Theme	Theme
1	At the beginning, suffering from redness around vagina for long time Very thirsty (Uses to drink a lot) Urinate a lot even in bed, urine	Nature of Type-I diabetes		
	infection Vertigo, lethargy and sleepy			
2	Frequent travel from home for treatment (Clinic)  Taken frequent medicine from clinic or medical shop (vitamins) for gaining the weight  Compromise in delay diagnosis  Final diagnosis after investigations  Unexpected result of investigations (high blood sugar level).  Admission intensive care unit	Experiences of diagnosis process	Experiences of treatment	
3	Child may have dry mouth Stay a sleep Complain headache Knew himself that got lazy on his back Weakness in legs Check blood sugar from glucometer Fed a spoon sugar chocolate Drinking hot water Fed an apple, pulses If not improving brought hospital directly	Need for treatment in emergency situation	journey	Variety of experiences of Type-I Diabetes
4	Facing severe hypoglycemic symptoms in child	Facing the diabetes complications		



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9	Result of sin act in previous life Why only god looks bad eyes me Toucher child from teacher in study Saying the child is worthless, valueless  Acceptance the disease seeing another child suffering from the same disease Felt that other have more pain than I have Feeling comfortable and familiar with the situation after treatment Accepted and adopted situation Gradually condition and habituation Managing the child's diet even with the child's inappropriate Monitoring child's blood sugar level and recording daily Managing the child's insulin administration daily Managing the exercise even if the Child's inappropriate cooperation.	Coping with challenges  Facing the care management challenges	Altering Life style	
11	Parents' satisfaction from Appropriate cooperation from health care professionals (doctor, nurses) The mother's satisfaction from appropriate cooperation of husband's in the child's care	Strong sharing the care	Support	Striving to live an ordinary family life
12	The parents attempt to acquire knowledge about child management	Acquisition of Knowledge	system	



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	of type I diabetes (diet, blood sugar monitoring from health care provider nurse) The parents attempt to practice skill to inject insulin administration Acquiring knowledge and skills through the personal study	skill	
13	Concern about child's marriage Concern about unpredictability of the child condition Worry about not getting opportunity due to disease condition	Concern about the child's future	

Result of the study on lived experiences of parents with children of Type I diabetes. The analysis was based on individual depth interviews on how eleven parents with children of diabetes type-I experienced their role as a parent. There were eight mothers and three fathers in the study and the duration of being parent to a child with Type-I diabetes ranged from 6 to 12 years, diagnosed for at least six months. The family structure varied, ten parents lived in families and one parent lived as single mother (divorcee). Furthermore, education occupation and income varied. On the basis of analysis findings are described below:

### **Sociodemographic Characteristics of Participants**

Sociodemographic characteristics of participants are presented in term of age, address, occupation, educational level, employment status of parents, children's age at diagnosis, duration of diagnosis of children.

Table 1
Socio-demography characteristic of Parents n=11

<b>Demographic Characteristics</b>	Frequency	
Age Group		
Below 30	3	
30 to 40	4	
Above 40	4	
Ethnicity		
Madesi	2	
Brahmin/ Chhetri	7	
Janajati	2	



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<b>Educational Status</b>			
Bachelors	2		
Higher Secondary Level	6		
Secondary Level	3		
Occupation			
House maker	3		
Bussiness /Trekking	4+1		
Teacher/Jobholder/Tailoring	1+1+1		
Type of Family			
Nuclear	9		
Joint	2		

Table 1 depicts that the age of the participants varied from 23 years to 45 years. Regarding the occupation of participants, three of them were house makers, four were business men, one of them did tailoring, one of them did trekking and one of them was a teacher and one of them a jobholder. Participants were three fathers and eight mothers.

Table 2
Socio-demography Characteristics of Children n=11

<b>Demographic Characteristics</b>	Frequency	
Age Group		
6-9 Yrs	7	
10-12 yrs	4	
Gender		
Male	6	
Female	5	
<b>Duration of</b> Diagnosis		
3  months - 3  yrs.	8	
4 yrs 5 yrs.	3	

The children age were 6 years to 12 years. Duration of diagnosis age of children were 7 months to 5 years.

### **Finding of In- depth Interview**

Lived experiences of parents of children having type- I diabetes are presented under two major emergent themes. Integrating codes and categories from all transcript produced a master table themes with their subthemes and categories. There are two emergent themes with four subthemes and 13 categories.



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Table - 3
Emergent Themes with their Sub-themes and Categories

S,N	Categories	Sub themes	<b>Emergent Themes</b>
1	Nature of Type-I diabetes		
		<b>Experiences</b> of	
2	Experiences of diagnosis process	Treatment journey	
3	Need for treatment in emergency		
	situation		
4	Facing the diabetes complication		Variety of experience
5	Emotional challenges	Emotional/	of Type I diabetes
6	Hopeless and helplessness	Psychosocial	
7	Facing the financial problems	consequences	
8	Social treatment after diagnosis		
9	Coping with challenges	Altering Life style	Striving to live
10	Facing the care management challenges		an ordinary
11	Strong sharing the care	Support System	family life
12	Acquisition of knowledge and skill		
13	Concern about the child's future		

Each theme is described by their sub themes and categories, which are supported by quotations in the interview for the purpose of the catching multi- dimensional aspects of experiences of the study participants. Verbatim quotes from data are italicized.

### Variety of experiences of type I diabetes

This emergent theme is explained under the sub theme experiences of treatment journey. The sub theme experiences of treatment journey have further four categories nature of Type-I diabetes, experiences of diagnosis process, need for treatment in emergency situation, facing the diabetes complication.

### Experiences of treatment journey

Majority of the participants said that they didn't known the causes of disease but some of them reported that it was due to hereditary reason. A Parent was terrified that his child had got a deadly illness like depression or a brain tumor. His child had blood sugar. He thanked God as the disease could be treated. He said "We continuously took our child to doctor, but it was not diagnosed. We gave him Chakku, but it functioned as poison for him."

### • Nature of Type-I diabetes

Most of participants said that children became thin, experienced excessive urinating leakage even in bed, thirsty and itching in private parts and did not recover for long time. Some participants faced a feeling of guilt due to inadequate understanding of the initial symptoms of the



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child's disease. Some of them said 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. Participant said, "My daughter's health was detorating, grossly weight loss even if normal intake. I always thought that it was related to growing age, so I delayed the clinic visit because I didn't know the diabetes signs and symptoms."

### • Experiences of diagnosis process

Majority of the participants said that they didn't known the causes of disease but some of them reported that it was due to hereditary reason. A few was entirely surprised by the diagnosis. Father said, "Before investigation, I was terrified my child had got a deadly illness like depression or a brain tumor and blood cancer according to doctor"

### • Facing the diabetes complication

Parents facing the complications of type I diabetes made their 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 parents in bad conditions.

Father said, "I am very sad I cannot go leaving alone the child because he had fainted and became serious, no one there, suffered from diabetes ketoacidosis(DKA). Neighbor brought him hospital. thanks god he survived" Mother said, "My daughter was repeadly attacked from DKA why that occurred, I didn't know. I immediately brought her in hospital, so she survived".

#### • Need for treatment in emergency situation

Emergency, depending on the age of the child and how their symptoms manifested, signs of high or low blood sugars can go undetected for a period of time. Six, seven years' children are not always able to communicate their feelings of low or high blood sugars, so parents have to be vigilant in watching them, so they can recognize their change quickly. A Mother expressed, "My child used to drink a lot, stayed asleep and she complained headache" at that time, I used to give her hot water and added two- line insulin to inject her" If she did not get well, I used to bring her hospital immediately."

#### Emotional/Psychosocial consequence

Feelings included grief at the permanent loss of the child's previous health status and loss of family as a unit they had once known. One parent stated, "I went through a grieving process, and I knew grieve for me near death ... but I still have to grieve for the loss of my healthy child.

### • Emotional challenges

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 life, disease condition, and future consequences.



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A parent expressed frequent emotion. A mother expressed, "This child born after treatment. All said, this disease was inheritance. I felt as if I fell down the stream when my child diagnosed with type I diabetes".

#### Hopeless and helplessness

Feelings of sadness and compassion were apparent, especially when parents had to undertake invasive procedures on the child with T1D such as blood-sugar monitoring and administration of subcutaneous insulin. Parents expressed frustration with the unyielding effort required to manage their child's condition, including the general lack of understanding from others. A mother commented:

"It was biggest frustration for me when my child was diagnosed with type I diabetes. I knew people just didn't realize the constantans of it, that's what I found exhausting."

### • Facing the financial problems

Most of the parents reported that investigations cost was so expensive.

Insulin and glucometer were free in KCH but others interventions cost was expensive. A mother said "The financial challenges, the investigations are also expensive. use syringe and needles four times a day" Also, the transport to the hospital was expensive." It was difficult but we had to do it for our child because I didn't have anybody else." I cannot manage diabetic diet due to lack of money."

#### • Social treatment after diagnosis

Parents noted that although they have a desire for their children to maintain normal activities, they find it hard to let them go. Participant said "My child said, he did not like to go to the party because he should not eat any food in party." I also did not go to the party because people often ask me about my child's diabetes condition, which I did not want them to ask."

### Striving to live an ordinary family life

Family transition to a new way of living occurred from diagnosis. Loss and disruption, the first stage of the transition, was initiated by the unexpected diagnosis of childhood T1D. The succeeding stage, acceptance and adaptation, necessitated the implementation of strategies for the family to negotiate for the beneficial transition to a new, albeit different way of living.

### Altering Life style

It was hard to accept the reality of their child's long term treatment and they felt overwhelmed by the new situation. The parents described that at first they did not understand what was going on, even though they had been worried about the child's health prior to the diagnosis. They had to get familiar with the new situation, which was challenging. Both mothers and fathers talked about a period of grief which took time to work through, and that was still going on. Even if the situation was no longer experienced to be as dramatic as in the beginning, feelings of despair could easily arise. A mother expressed, "Child was the world for me" I could not imagine that situation. I cried a lot with God in hospital temple. But as time went by there was not the same,



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realized about the whole thing, but I still felt the despair and the loneliness when I let it come to me.

After about 6 months, however, the parents were more familiar with the situation. They became habituated. When looking back in time, they felt they had been very sad. At the time around diagnosis, they talked about the imperative of learning very much, they very quickly learned and developed skill to inject insulin. A mother expressed, *the first time, when I learnt to inject insulin, my hands were shaking but not now I can inject but still I am not competent.*"

#### • Coping with challenges

A mother expressed, "At first, it was very difficult for me. There is no such disease at home or in the village. So, I felt only my child suffered from this disease. But now I saw so many cases in hospital and then I accepted it"

Another mother expressed, "When I wake up in the morning I usually test my sugars and then I injected insulin, and then I usually wait for 15 minutes before I take breakfast. After that I wait until around 10 am I also did that during lunchtime. This was habitual for me".

#### • Facing the care management challenges

The majority of the participants faced management challenges about diabetes care. The importance of balanced nutrition for diabetes management, in addition to the use of snacks for controlling blood sugar, was clearly evident to children from a young age.

A parent said, "My child should eat low sugar diet, but whatever she sees, she wants to eat. She cannot control herself, and sometime eats cake, her blood sugar goes up." I do not really know what to do"

Another parent explained, "I always fear the failing of managing the daily diet. Child's health and life was detorating day by day and I had a little knowledge about diabetes diet".

A father said, "I use finger sticks to take the blood out to check up sugar level, daughter wept and I feltl so sad."

Another aspect of disease management is insulin handling. Participants stated that the administration of a painful procedure like the insulin injection was very painful for them.

A mother expressed, "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 husband to inject the insulin, now I thought this was like eating food."

One father said, "It really hit me as a father; my child needed these injections to stay alive".

Lack of portable storage facilities also resulted in children altering their insulin dosing schedule, potentially posing a threat to sugar control: Mother said, "One problem I had the storage of insulin. I usually store it in a cool place. I had no fridge. I was usually forced to take my morning dose the previous evening as I did not have proper storage for it."



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The majority of the mothers stated that their husbands had participated side by side in the care and management of their children. At hospital doctors and nurses provided us with advices we need. Even family members helped us equally. A participant said, "My father sent me money for my child treatment."

### • Strong sharing the care

The majority of the mothers stated that their husbands had participated side by side in the care and management of their children. At hospital doctors and nurses provided us with advices we need. Even family members helped us equally. The mother's satisfaction from appropriate cooperation of her husband in the child's affairs.

A mother said, "my husband loved her more than I did, he kept her with himself at night because he thought that something bad might happen to her."

### • Acquisition of knowledge and skill

The majority of participant said that they had not neglected anything in this regard, and taken all opportunities to increase their knowledge, skill because they felt that there would still be some information and skill that they needed to know. They followed a trusted sources health personnel:

Participant said "I regularly went to the endocrine OPD in hospital. I still need their training to inject insulin and I really like to learn everything".

Likewise, another father said, "received skill to inject and information about management of type I diabetes from here were somewhat useful, but I acquired more knowledge by reading books and browsing websites on the internet".)

One mother said "I gathered information by speaking to other mothers. I think that these were more useful for me as I learned more."

In summary, all participants received acquisition skill to inject insulin and information about type I diabetes management from hospital. Participants expressed that health personnel support them adequately in sharing information for diabetes management, they taught about how to care child and consult them unpredictable conditions for the child.

#### • Concern about the child future

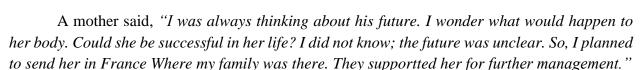
All participants described a good future for their children but one parent hoped for increased knowledge in the wider society. Most participants in the study explained about the child's future because they knew that diabetes was a threat to children's health and its complications may affect them later. These mothers were obsessed with presumptions of a vague and uncertain future for their children. Anyway, all participants hope a good future for their children.



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Another area of concern for these participants 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? Smilarly, father said that "nobody can marry him (son) because he is suffering from diabetes. So, I had planned to send him Gumba in India for study so that he remained unmarried. Buddhists in the Gumba's helped him face the obstacle in life." mother said that "It's so hard for a girl, especially in our society. When she wanted to get married, would anyone be interested in her? my husband got worried about her marriage." Another father explained "I could not fulfill the child's dream because he wanted to be a football player but he could not do due to disease condition."

#### Conclusion

The main aim of this study was to explore lived experiences of parents of children having type I diabetes. Parents faced several problems while caring the children such as insulin administration, blood glucose monitoring and diet management. Parents experienced different emotional as well as psychological problems in their day-to-day life such as they become upset while thinking about their children life, disease condition, and future consequences. The majority of the parents experienced strong support system from family members and hospital staffs.

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 as well as while caring the children such as insulin administration, blood glucose monitoring and diet management. Intervention studies examining the effect of provision of psychosocial support to families may further improve nursing practice.

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