

## **Understanding Mothers of Children with Type 1 Diabetes: An Investigation of Perspective and Management**

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**Abstract :** Families with children with type 1 diabetes (T1D) encounter many stressful experiences. The mother is a significant person in taking care of a child's diabetes. However, little is known about the experiences of mothers living with a child with T1D in Thailand. This study aimed to describe mothers' definition of their predicament, management behaviors and consequences of having a child with T1D. A descriptive qualitative approach was used, and data were elicited from interviewing 22 mothers living with a child aged 6-12 with T1D. Content analysis was used for data analysis.

It is found that both mothers who perceived T1D was a non-life threatening and serious disease could manage their disease. The meaning of having a child with T1D was either part of life or as a situation beset with dukkha (the Buddhist concept of suffering). Most mothers could manage the disease even though some perceived that they were burdened by it. Major activities included diabetes management activities and day to day management activities. The difficulty of balance family relationships, social life, lifestyle and finances was found in some families.

The findings indicated that understanding of mothers' response to the illness situation was a crucial guideline for supporting the family and lead to further clinical exploration and research.

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**Key words:** mothers, school-age children, type 1 diabetes, perspective, management

### **Introduction**

Type 1 diabetes (T1D) has been one of the most common chronic conditions affecting Thai children. The incidence rate of T1D in Thailand has dramatically risen.<sup>1</sup> The peak time of the onset for diabetes in children in Thailand is in school-age children (nine - 12 years of age).<sup>2</sup> During the illness, children with T1D may suffer from many short-term and long-term complications. Several studies support the idea that the development of

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complications is related to how well the disease is controlled.

In every day life, children with T1D are required to adhere to a strict treatment regimen in order to confine blood glucose level within a target range. Daily diabetes therapy consists of two or three insulin injections, self-monitoring of blood glucose, careful regulation of dietary intake, and exercise. Despite the possibility of control of blood glucose levels, children with T1D continue to have a chronic condition, affecting not only the children themselves but also the whole family, especially in school-age children. They still need others, usually parents, to help them, so this situation has an impact on the family as a whole. As a consequence, T1D can be a stressful, demanding experience for both the children and the whole family.<sup>3-5</sup>

In Thailand, children with T1D and their families has not been studied. The existing studies of children with T1D and their families in western families may not represent experiences of children with T1D in Thai families because of the different cultures, contexts and religions. Therefore families with T1D who have different cultures may have different perspectives in coping with their child's illness.<sup>3-5</sup> Moreover, nurses and healthcare professionals who care for Thai children and families with T1D are typically more concerned about disease control and prevention of complications than the family context of illness management. They may not completely understand the ways families respond to this situation. In order to support Thai families with T1D effectively, nurses and healthcare professionals need to adequately understand the family's problems, the family's response, and the coping strategies that the family use to manage their daily lives.

Family management style<sup>6</sup> could describe how the individuals and the family as a unit responded to a child's chronic condition. The emphasis was on how families defined their areas of concern and the relationship of these definitions to their management behaviors and perceptions of consequences of the illness. Although the family is a system consisting of different members, Thai mothers are expected to provide important information about the relationship between family members and the family as a unit. A qualitative descriptive design was appropriate for this study as little is known about the phenomena.<sup>7-8</sup> The study aimed to describe (a) definition, (b) management behaviors, and (c) perceived consequences of having a child with T1D.

### **Participants**

A purposive sample consisting of 22 participants was obtained from Thai mothers of children who came to the diabetes outpatient clinic for follow up at five hospitals in Bangkok, Thailand. Their children were diagnosed with T1D for more than one year, school-age children between 6 and 12 years old and did not have severe complications such as diabetic retinopathy or renal disease. The participant mothers represented a variety of aged, educational, occupational, incoming backgrounds. However, they were more homogeneous in terms of religion, as 21 mothers (95.5%) were Buddhist. The children with T1D were the same numbers of boys and girls. The mean age of them was 9.95 years. They ranged in age from 2 to 11 years old at time of diagnosis, with an average age of 6 years old. The length of time since diagnosis ranged from one to 9 years, with an average age of 4 years. However, all these children had a higher level of HbA1c (7.2-13%) than the normal healthy range (7-8%), with an average age of 8.98%.

### **Data collection procedures**

Approval of this study was obtained from the ethics committees of each hospital. After receiving permission to recruit subjects and access hospitals records, the researcher contacted pediatric endocrinologists and/or clinical staffs and provided them with the information regarding this study. They were asked to contact potential participants. After participants agreed to take part in the study, a complete explanation and a written description of the study were given to the participants and they were asked to sign the informed consent form before data collection started. After that taped-recorded, open-ended interviews were conducted with each participant.

The interview was asked general questions concerning how mothers defined and managed their situations. Interviews lasting between 30 and 180 minutes were conducted privately and individually, with participants selecting the interview site. Fourteen participants selected to be interviewed at their home. As for the rest, they chose their workplace, a private zone at the outpatient clinic in the hospital and the school of their children as the place for data collection. Of the 22 participants, four were interviewed twice to expand some points of views. For the other participants, the researcher considered that the data drawn from them were rich enough, so it was unnecessary to have the second interview. The participants were also assured that they could discontinue their participation in this study at any time if they wished and their refusal to participate would not affect the medical care and they would receive in the future in any way.

### **Data analysis**

The process of data analysis began at the time of the first interview that was transcribed verbatim

until the writing of the findings was finished, lasting over one year and six months. Content analysis was used to analyze the data following the descriptive main components: Defining, managing, and perceived consequences of the illness. The researcher started the process by transcribing verbatim the tape recordings in Thai then added nonverbal responses of the participants from field notes in the transcripts. In order to develop the coding process, the researcher had to define the unit of analysis which was defined as complete thoughts and ideas in a phrase, a sentence, or a group of sentences which were expressed by the participants. Then the researcher used this unit of analysis to code the transcripts of all participants. In the meantime, the co-researcher independently coded the transcripts. Finally, the dimensions, themes and sub-themes were translated into English.

In order to reach trustworthiness of the study, the researcher used purposive sampling to develop a rich description of family with school-aged children with T1D by Thai mothers. The triangulation technique was used in order to improve the probability that findings and interpretations. They employed many data collection techniques including interviews, field note observation and memo-writing. In the interviewing, the researcher employed enough time with each participant to gain trust and obtain full understanding of their illness situation. Moreover, the researcher interviewed two mothers as a tryout in order to validate the interview technique of the researcher. Also the researcher interviewed some mothers twice to validate the some points of views.

### **Findings**

Three major aspects of mothers with children with T1D could be described following the research questions-definition of the situation, management

behaviors, and perceived consequences of having a child with T1D. Eleven dimensions, twenty-one

themes emerged from qualitative study. The summary of each item is shown in **Table 1**.

**Table 1** Components, dimensions, themes related to perceptions of being mothers of children with T1D

Components	Dimensions	Themes
Definition of the situation	Viewing the child	Normal Unique
	Perception of the illness	Non-life threatening Serious
	Meaning of having a child with T1D	Normal Suffering
	Perceiving ability to manage the illness	Manageable Un-Manageable
Management behaviors	Management goal	Maintaining normal blood glucose Fostering a child's independence
	Diabetes management	Giving insulin injections Monitoring and preparing dietary intake Monitoring blood glucose level Encouraging a child to have an exercise Taking a child for follow-ups
	Day-to-day management	Encouraging self-care to a child with T1D Keeping a child's identity Meeting the child's development needs Identifying social support Seeking alternative medicine Accepting the child's illness Coping with day-to-day stress
Perceived consequences	Family relationships	Closer parent relationship Parental conflict regarding diabetes management Parent-child conflict regarding diabetes management Parent-sibling relationship conflict
	Lifestyle	Healthier lifestyle Difficulty changing dietary intake
	Social life	Child having difficulty at school Difficulty following DM regimens when away from home
	Financial security	Difficulty maintaining a balanced budget

## Definition of having a child with T1D

The mothers in this study showed that the definition of the situation was defined by how the mothers viewed the child, how they perceived the illness, how they defined the meaning of the illness, and how they perceived ability to manage T1D.

**Viewing the child**, the mothers viewed their children with T1D and their abilities as either normal or unique when compared to other children.

*Viewing a child as normal* refers to mothers (n = 16) who perceived that their children with T1D were normal and could take care of themselves as normal. The description of normal was derived from the children's capability and their figure. One mother described her son as "He was a normal, ordinary child, and nothing had happened."

*Viewing a child as unique* refers to mothers (n = 6) who perceived that their children with T1D were different from other healthy children. The description of unique was derived from mood and activities of their children with T1D, receiving special privileges, getting more attention from parents, relatives, or school teachers or not taking care of themselves.

**Perception of the illness** refers to mothers' view of the illness at the time of the interview. The mothers in this study described two main views of the illness: A non-life threatening illness and a serious disease.

*Perceiving T1D as non-life threatening* means mothers (n = 15) perceived that T1D was not a serious problem and they could take care of it. Most of them usually had good experiences with the children's illness and felt sure that they could control the disease. One mother shared her experience with T1D as:

Diabetes is a disease that could be controlled. If you had a good control of it, your children would be healthy.

*Perceiving T1D as a serious disease* means the mothers (n = 7) perceived that T1D was a life threatening disease and their children could die from it. These mothers usually had bad experiences with the disease. One mother shared her illness view as:

Diabetes was a horrible disease, especially wounds. One thing that I was very concerned with was that she might become blind.

**Meaning of having a child with T1D** refers to the perception of mothers about having a child with T1D in a family. The mothers in this study showed that this situation made them had *dukkha*. According to Buddhist philosophy, *dukkha* is usually related to pain, illness, and death. *Dukkha* is often translated as "suffering" in English. However, the right meaning of *dukkha* involves the whole existence, including happiness, suffering, like, dislike, and a pleasant or unpleasant condition.<sup>9-10</sup> Buddhists believe that *dukkha* is unavoidable. The mothers of children with T1D were certain to face with *dukkha* in daily life. They all perceived it in a negative way.

Therefore, *dukkha* in this study refers to suffering, both physically and spiritually. Since the mothers faced with the illness situations of their children which were unexpected and difficult to deal with, including managing diabetes, experiencing uncertainty related to symptoms and prognosis, and also searching for the cause of having a child with T1D.

*Suffering from diabetes management* refers to the mothers who had suffering and stress caused by diabetes management in daily life such as from seeing a child in pain from injections, forbidding a

child to eat what they liked or controlling children to follow the treatment regimen. A mother with a 12-year-old girl explained her suffering when having children with T1D as follows:

I suffered when I saw my daughter had to be injected with insulin every day. My daughter might get accustomed to it, but for a woman who was a mother, I felt...Oh no, my daughter must inject it every day. I could not stand it. (Mother cried).

*Suffering from uncertainty related to symptoms and prognosis* means the mothers suffered and were distressed from being unable to predict their child's condition. They were afraid of severe complications of T1D.

*Suffering from searching for the cause of having a child with T1D* means the mothers remained in their suffering from making sense of having children with T1D in their family. Ten mothers said that until then they had a question of "why it happened to my child?"

Although suffering is unavoidable, Buddhists believe that we could live with suffering while leading a normal life. The way to do this is to recognize that there is suffering and then try to understand the nature of suffering. It is what it is, and people should react to suffering without judging its value.<sup>9</sup> Thus half of the mothers (n = 11) reflected that whether they had children with T1D or not their life remained normal. For example, a mother of a 12-year-old boy insisted "No problem, we are fine and normal."

Therefore, the meaning of having a child with T1D could be divided into two groups. First, *normal*, as the mothers faced with suffering in any T1D situations, but they could accept it and live a normal life. On the other hand, some mothers faced

with suffering, and suffering had become the biggest and most prominent factor beyond which they could not see.

**Perceiving ability to managing the illness** refers to the subjective aspect of the mothers about how easy or difficult it was for them to manage T1D treatment regimen. Two main views of the mothers were that it was either manageable or un-manageable.

*Manageable* means the mothers had a positive perception of their ability to integrate the child's T1D care into their lives and they were accustomed to the management situation. They recognized manageability as effortless or burdensome.

1. Effortless experience refers to the mothers who perceived that they had the ability to manage T1D treatment regimen as part of their daily life and to make their life go on. Eleven mothers were content with the incorporation of both the illness situation and day-to-day management into their family life. One mother who took care of a child with T1D for more than six years explained her ability as follows:

Diabetes activities were daily activities. You brushed your teeth in the morning and then you had something to add to her routine. You had to inject insulin. It was the same in the evening since you had to take a bath, brush your teeth, and then do the insulin injection... I had no problem with managing diabetes-injection, blood testing. It was fine.

The subjective aspect of mothers about their ability to manage T1D was compatible with the meaning of having a child with T1D. This is because all mothers who perceived that they could manage T1D also perceived that having a child with T1D was normal.

2. Burden experiences means the mothers perceived that they had the ability to manage the T1D treatment regimen in their everyday lives, but this situation was difficult and made them very worried about being responsible for it. Eight mothers asserted that they were burdensome. One example can be found in a mother of a 12-year-old boy who stated:

He thought that I did not care for him. I was busy. I just came back from work and found that he had not done any diabetes activities. I felt tired and wondered if I had to tell him to do everything again and again. Why wasn't he responsible for anything? I felt very tired from work and also this task. It was a heavy burden on me.

*Un-manageable* means the mothers perceived that managing the T1D treatment regimen was not easy and they were unable to do it. Three mothers confirmed that they did not have the ability to manage all T1D managements of their children since they were unable to control their children to follow the diabetes treatment regimen. These three children were entering the adolescence period, and they started to perform all T1D activities by themselves, but they did not follow them strictly. One mother discussed her 12-year-old girl:

I was absolutely unable to manage the disease because I couldn't control my daughter... It was unbelievable that the disease happened to children since we couldn't control their food eating habits, especially desserts. All children liked desserts.

It was found that mothers who perceived that managing the T1D situation was a burden or un-manageable on them also perceived that they had suffering from having a child with T1D. There were some factors that had significant influence on their perceptions such as a child's condition, a child's and parents' characteristics, social support, financial support, past experiences with T1D, and background knowledge.

### **Management behaviors**

Management behaviors refer to discrete behavioral adaptations that the mothers used to manage their daily life. The findings revealed that three major dimensions had emerged and been identified: Management goals, diabetes management and day-to-day management.

**Management goals** refer to goals of mothers that underlay the overall approach and management of children with T1D. Maintaining normal blood glucose and fostering the child's independence were management goals of these mothers. They could have both goals, but 16 of them may have paid more attention to the first goal, while the others gave more significance to fostering the child's independence.

**Diabetes management** refers to behaviors of the mothers related to managing T1D activities and incorporating it into daily life. Basic diabetes treatments for children with T1D in Thailand involves giving insulin injections, monitoring and preparing diets, testing blood glucose levels, encouraging the child to exercise, and taking the child for follow-ups in order to keep their blood glucose level within the normal range. These five activities were described in three general behavior approaches: Strict adherence, flexible adherence, and non-adherence. Adherence in this study meant the mothers with children with T1D developed behaviors from the diabetes treatment regimens prescribed by healthcare professionals to meet their desired goals.<sup>11</sup>

*Giving insulin injections* refers to the action of the mothers when injecting the child with insulin twice a day as part of the child's routine in order to control blood glucose levels within a healthy, normal range. The findings of this study reflected two approaches: Strict and flexible adherence. No mothers in this study could be categorized as non-adherence when it came to this practice.

1. Strict adherence refers to the mothers who followed the insulin prescription exactly and regularly. Ten mothers in this study never adjusted the dosage of insulin by themselves.

2. Flexible adherence refers to the mothers who adapted the dosage of insulin to ensure that the blood glucose level was well within the normal range under the physician's supervision and recommendation. Twelve mothers understood how much doses that they should add, and if they had any problems about that, they would call the diabetes team to confirm their adjustment.

*Monitoring and preparing dietary intake* refers to actions of the mothers in paying attention to the child's meals and snacks: "What and when should the child eat?" to follow the T1D treatment regimen. In this study, three general approaches were found regarding this activity: Strict, flexible, and non-adherence.

1. Strict adherence refers to the mothers preparing meals and snacks for the child through standard meal plans of T1D with strict calorie counts. There was only one mother in this study who was able to strictly follow this. She confirmed that in the past six years, she had prepared every meal and snack for her child.

2. Flexible adherence referred to the mothers who adapted meals and snacks to a certain extent to make life more livable but still strictly followed the treatment regimen. Eighteen of the mothers in this

study used this strategy since they found that their children were too young to refrain from eating something that they liked. Thus, they would adjust some ingredients for the children's food in order to help them eat some kinds of food that they liked without having hyperglycemia.

3. Non-adherence refers to the mothers allowing the child to have meals and snacks that were not part of the diabetes meal plan at all. Three mothers in this study reported that they could not stick to the diabetes meal plan since they could not control the children's eating behavior. Also, these three children were entering their adolescence. They wanted to get freedom to do what they wanted including selecting their own food, so the mothers could not force them to follow it.

*Monitoring blood glucose level* refers to the mothers carefully watching blood glucose level. In the diabetes regimen, endocrinologist recommended the child with T1D to monitor their blood glucose level at least two times per day in order to inspect whether it was too high or too low or to prevent diabetes complications. However, four of the mothers in this study were unable to support their children with T1D to test blood glucose level regularly due to the high price of glucostrips.

*Encouraging a child to have an exercise* refers to the mothers' persuading their children to have regular exercises. The children in this study were in the school age, so they preferred to play or have activities with their friends. The mothers just only encouraged them to do it appropriately.

*Taking a child for follow-ups* refers to the mothers' taking the children to the follow-ups with physicians at the hospital. Almost all of the mothers realized that the physicians' recommendations were meaningful and valuable for them.



The findings of this study regarding diabetes management showed that most of the mothers with children with T1D performed good adherence (strict or flexible adherence) to injecting the child with insulin, encouraging the child to have an exercise, and taking the child for follow-ups. The aim of these mothers was to maintain normal blood glucose level into normal healthy range. However, some of the mothers did not adhere to the prescribed regimen of monitoring and preparing dietary intake and testing blood glucose.

**Day-to-day management** refers to behaviors of the mothers in taking routine care of their children and also enhancing diabetes treatment activities. Mothers with children with T1D performed maternal roles such as encouraging self-care, keeping the child's identity, meeting the child's development needs, identifying social support, seeking alternative medicine, accepting the child's illness, and coping with day-to-day stress.

*Encouraging self-care of the child with T1D* refers to strategies the mothers used to encourage the children to have more independence and autonomy such as skill training, close supervision and maternal reminders.

*Keeping the child's identity* refers to strategies of the mothers to protect the privacy of their children with T1D. Although T1D was not a contagious disease, eight children from the study felt ashamed about having T1D. Their mothers were aware of their children's feeling and tried to conceal the condition and made it known only among family members. However, the rest of mothers were not concerned with keeping it a secret and they all let people around them know that their children had T1D. They believed that if something was wrong with their children, they could help them such as giving them a candy when they had hypoglycemia.

*Meeting the child's developmental needs* refers to the strategies that the mothers used to raise their children with T1D in daily life. Because their children had T1D, parents tried to allow them to do what they liked in order to respond to their needs and to make them feel happy and satisfied. They would respond to basic needs of their children in bio-psycho-social-spiritual area. However some mothers thought that their children were sick, and no one knew when they would die, so they would allow them to do as they desired more than in the past.

*Identifying social support* refers to the strategies the mothers used to seek social support to help them manage children with T1D. Healthcare professionals, teachers, friends, and relatives were the sources of help that all mothers utilized in order to achieve their management activities in this study.

*Seeking alternative medicines* refers to the strategies of the mothers used to try other sources of medicine to cure T1D. Eleven mothers in this study tried to use alternative medicines such as herbs or Chinese medicine. Some of the mothers used alternative medicines in combination with modern medicines, while others stopped modern medicines in order to test how well alternative medicine worked.

*Accepting the child's illness* refers to strategies of mother to manage their mind to acknowledge the illness situation that happened with their children. Thai mothers in this study indicated that they used the word "thamjai" to accept the child's illness. In the Thai culture, 'tham' means "to do or act," while 'jai' means "heart or mind." Therefore, 'thamjai' referred to managing one's mind so as to move towards understanding and accepting of an unpleasant or painful situation.<sup>12</sup> According to the study findings, comparing self with others and blaming *Karma* (the cause and effect of volitional

activities and actions in previous life) were two of the *thamjai* strategies that the Thai mothers used to live with their child's illness.

*Coping with day-to-day stress* refers to the strategies that were used by the mothers to manage stressors from everyday hassles. In this study, it was discovered that the mothers used four strategies to help them reduce stress; participating in a religious ceremony, being patient, walking away, and thought stopping.

In summary, all the mothers in this study performed both diabetes management and day-to-day management in order to achieve their management goals. Besides, it might be summarized that receiving social support, accepting the child's illness, and using coping strategies to manage day-to-day stress could assist the mothers of children with T1D in this study to live their life as normally as possible.

### **Perceived consequences of having a child with T1D**

The consequences of having a child with T1D refers to experiences of family members after having a child with T1D as described through the mothers' perceptions. The four major dimensions were identified: impacts of T1D on family relationships, impacts of T1D on lifestyles, impacts of T1D on social life, and impacts of T1D on financial security.

**Impacts of T1D on family relationships** refer to the consequences after having a child with T1D in a family regarding the interaction of two members in the family. The findings indicated that four themes were identified: Closer parental relationships, parental conflicts regarding T1D management, parent-child conflicts regarding T1D management, and parent-siblings relationship conflicts.

*Closer parental relationships* refer to how T1D brought the parents closer together. A number of mothers (n = 6) asserted that their husbands became

warmer and nicer to them after the diagnosis of T1D of their children. They said that their husbands were also more concerned with her well-being and became involved in taking care of the child with T1D.

*Parental conflicts regarding T1D management* refers to T1D management situations that caused parents of a child with T1D trouble in the relationship with their spouses. Most of the conflicts arose from disagreements about how to take care of the child with T1D, how to deal with their grandmothers, and how to manage the T1D expenses.

*Parent-child conflicts regarding T1D management* refers to the T1D management situation that made parents and children with T1D develop conflicts with each other. Most of the mothers reported conflicts with their children over food, their children's emotional status, and misperception between parents and the child.

*Parent-sibling relationship conflicts* refer to the impact of having the child with T1D in the family, which led to misperceptions between parents and siblings. Contrary to the perception of children with T1D, siblings perceived that they received less attention from their parents.

**Impacts of T1D on lifestyle** refer to the consequences after having a child with T1D in the family that brought about changes in daily activities. Family members of the child with T1D either perceived that they became healthier or had difficulty changing dietary intake.

*Healthier lifestyle* refers to the fact that family members had an optimistic view of having a child with T1D in the family regarding T1D dietary intake. A few mothers and a child with T1D perceived that having T1D in a family made them have a good health since they learned about nutrition from appropriate diabetes dietary intake.

*Difficulty changing dietary habits* refers to family members having a pessimistic view of having a child with T1D in the family regarding dietary intake. A few mothers demonstrated that it was very difficult to change the types of food that they used to eat to meet T1D dietary requirements. At the same time, controlling the dietary intake of the child with T1D may have made some of the siblings feel as if they themselves also had T1D.

**Impacts of T1D on social life** refer to consequences of having a child with T1D in the family that resulted in changes in the family's social life. T1D negatively affected both the mothers when they went out and the children with T1D when they went to school.

**Impacts of T1D on financial security** refer to consequences of having a child with T1D in the family that resulted in managing diabetes expense. Due to costs of care, transportation fares, and miscellaneous expenses in managing children with T1D, six families in this study had to live with a huge financial burden. They could not balance the budget and encountered economic constraints.

Therefore, the consequences of having a child with T1D in the family reflected the degree of seriousness in taking care of the child with T1D. Families that showed a positive view of having a child with T1D were usually well-to-do families already having financial stability, whereas the families that were unable to think in a positive way mostly were already unable to manage the T1D situation.

## Discussion

Thai children with T1D and their families encountered with many stressful experiences and had their own perspective in living with the illness. Understanding definitions, management behaviors,

and perceived consequences of having a child with T1D could assist healthcare professionals to comprehend the illness situation of these families.

Regarding these Thai mothers' view of the child with T1D and the illness, a review of literature revealed that Thai mothers with children with T1D from this study did not considerably differ from the mothers with children with T1D in western cultures.<sup>13-15</sup> One plausible explanation is that T1D did not result in physical deformity of the child. The mothers perceived that T1D did not pose obstacles in normal physical development, so their children were able to do exactly the same things that their friends did. Moreover, the disease itself could not make their child die suddenly or unexpectedly.

It was clear from the Thai mothers' interviews that the meaning of having a child with T1D was suffering (*dukkha*). However, Buddhism believes that suffering is not present in the mind all the times if we understand what it is and seek ways to live with it. These mothers would perceive that having a child with T1D was normal. "Normal" in this study was defined as the mothers' being able to live with T1D and with suffering as normally as possible. The study findings were also consistent with the findings in Thai of Sethabouppha<sup>16</sup> who studied Buddhist family caregiving. In her study, it was discovered that the subjects described "caregiving was suffering." She also stated that "suffering" in Buddhist philosophy is viewed as "*dukkha*" which was apparent in caregivers' lives since they faced negative experiences in taking care of these patients at home. However, although the caregivers had continuous experience with *dukkha* during caregiving, Thai Buddhist caregivers were able to sustain their caregiving duties overtime. For these caregivers, they used Buddhist practices of compassion, caring, and

support, stress management, symptom management, treatment management, and acceptance to sustain them.

Although some mothers (n = 8) indicated that they had the ability to manage the illness, they still perceived that managing T1D was burdensome. One distinctive factor that was associated with burden of the mothers was support from others. These findings were in congruence with the studies in western cultures. The findings of Sullivan-Bolyai<sup>17</sup> showed that 28 mothers who had young children with T1D had a burden from facing the illness situation. These mothers felt that they had ongoing responsibility and fear. They, as a result, suffered from chronic sleep deprivation. They also stated that they took care of their children with limited support or help from others.

It is noteworthy that some children who were under the age of ten years old still had to depend on their mothers in managing diabetes treatment regimens as they were too young to do the whole T1D treatment regimens by themselves. On the other hand, older children were able to complete the T1D treatment regimens by themselves. For the latter, the mothers would act as a maternal reminder or a close supervisor instead of the key player. The study of Urban and Grey<sup>18</sup> also stated that children with T1D who was in school-age could perform many diabetes tasks with adult supervision and support with their diabetes care. Meanwhile children with T1D should be assuming significant responsibility for their own diabetes task by the age of 12.<sup>19</sup>

Another important point of diabetes management was related to monitoring and preparing dietary intake to a child with T1D. The findings of the study showed that most of the mothers with children with T1D were unable to carry out food habits sufficiently well. According to the study of Natamonkonchai<sup>20</sup> who explored food habits of

school-age children in Thailand, children liked unhealthy foods or junk foods such as candies, jellies, sweets, or snacks. Thus, it was not surprising that children with T1D in this study did not want to follow the diabetes treatment regimen since they wanted to do like other children did.

Besides performing diabetes management, the mothers in the present study performed day-to-day management to enhance diabetes management activities and achieve their management goal. The Thai mothers in this study spoke often about seeking social support. They identified social support in both negative and positive ways. Some mothers identified support from others as not helpful since they realized that those people made the situation more difficult to manage. On the other hand, other mothers stated that support of healthcare professionals, relatives, and friends enabled them to live with a child with T1D with normalcy. They provided both information and emotional support to them. The findings were similar to the findings reported in Japanese and Thai culture.<sup>21-22</sup> They found that support from others could assist mothers with children with chronic illness cope with the illness situation easily.

Besides, it is interesting to consider why Thai mothers used the *thamjai* strategy to accept the child's illness and why it was related to the mothers who defined meaning of having a child with T1D as normal in particular. The findings of this study were supported by those of a previous study regarding Thai families with childhood cancer conducted by Patoomwan.<sup>12</sup> In her study, the results revealed that parents with children with cancer moved forward to understanding and acceptance of the children's illness, death, and some aspects of life that were lost due to the children's illness by using the *thamjai* strategy. Some parents discovered that they could '*thamjai*' to accept their child's illness, whereas other

parents reflected that over a long period of time they hardly managed to achieve peace of mind. As a result, the strategies that were identified to handle the difficulty in accepting the child's illness were maintaining an optimistic view and hope, seeking support, and making comparison.

It was surprising that family members in this study perceived that T1D had some advantages for them. Since only mothers in this study reported that they had a closer relationship with their spouse after the child had T1D. Their husband began to help them take care of their child more than before and also gave emotional support to them when they faced difficult situations. Moreover, family members perceived that having T1D in the family made them have a better health status since they had to pay attention to their dietary intake as well. However, family members also perceived that having a child with T1D could negatively affect them. As regards family relationships of these families, the findings were similar to the findings of families with children with chronic illness in western cultures.<sup>3, 23-24</sup>

The mothers who had financial problems before having a child with T1D or earned a low income encountered problems maintaining a balanced budget. According to the Thai health insurance schemes, there was no complete coverage of diabetes expenses. The "Universal Coverage" policy would cover only the expenses of insulin, but the mothers with children with T1D still had to pay for other medical supplies such as glucostrips, syringes, and needles which were costly. Therefore, some mothers perceived that T1D affected their family life.

In summary, definition, management behaviors, and perceived consequences of having a child with T1D in the family from the mothers' perspective enabled healthcare professionals to gain insights into

how these mothers responded to an illness situation and also guide future research and nursing practices.

### **Implications of the study**

The mothers who had suffering from having a child with T1D usually had burden or inability to manage a child. Therefore, healthcare professionals should recognize their definition and assist them to live with it as normally as possible. Besides, hospitals should provide multidisciplinary team for children with T1D and their families. Since this team will disseminate crucial knowledge about diabetes, enhance management skills for diabetes and give emotional support when they faced with difficult situation. Moreover, nurses should plan to visit the mothers at home in order to be acquainted with them. Finally, healthcare professionals should pay attention to the role of the mothers when their children entered to be adolescent. It should gradually be reduced; the children should learn to cope with the situation on their own with their mother providing only guidelines and supervision.

Future research should focus on families with children with various ages such as pre-school age and adolescents since they may have different perspectives in managing the T1D situation. A longitudinal research study is needed to assist healthcare providers to understand how the responses to the complications of the disease and the effects change over time as the children are growing up.

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# การรับรู้และการจัดการของมารดาที่มีบุตรป่วยเป็นโรคเบาหวานชนิดที่ 1

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**บทคัดย่อ :** การวิจัยเชิงคุณภาพนี้มีวัตถุประสงค์เพื่อศึกษาการรับรู้และการจัดการของมารดาที่มีบุตรด้วยโรคเบาหวานชนิดที่ 1 โดยสัมภาษณ์มารดาจำนวน 22 คนที่มีบุตรอายุ 6-12 ปีและเป็นโรคเบาหวานชนิดที่ 1 ผลการศึกษาพบว่า มารดาบางคนให้ความหมายของการที่มีบุตรป่วยในครอบครัวเป็นเรื่องปกติ ส่วนบางคนมองว่าเป็นเรื่องที่ทำให้เกิดทุกข์ และมารดาเหล่านี้มีทั้งรับรู้ว่าคุณเองสามารถจัดการกับโรคนี้อย่างไรได้และไม่ได้ รวมทั้งบางคนมองว่าการจัดการนี้เป็นภาระ ส่วนกิจกรรมที่มารดาต้องจัดการในแต่ละวันคือ การจัดการกับโรคตามแผนการรักษาของแพทย์และการดูแลในเรื่องต่างๆ ไป นอกจากนี้มารดายังรับรู้ว่าคุณเองและสมาชิกครอบครัวได้รับผลกระทบในทางที่ไม่ดีจากการที่มีบุตรป่วยเป็นโรคเบาหวานชนิดที่ 1 ในครอบครัว

การเข้าใจความหมายและการจัดการของครอบครัวที่มีบุตรป่วยผ่านทางมารดาทำให้ทีมสุขภาพเข้าใจถึงความยากลำบากในการจัดการของแต่ละครอบครัวและนอกจากนี้ยังช่วยขยายความรู้เกี่ยวกับครอบครัวที่มีบุตรป่วยเป็นเบาหวานชนิดที่ 1 ให้สามารถพัฒนาให้เห็นถึงความสัมพันธ์ของปัจจัยที่มีผลต่อการจัดการรูปแบบต่างๆ ต่อไป

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