The Process of Managing the Children with Type 1 Diabetes in the Family: A Grounded Theory Study

Abstract

Background: Diabetes is a disease that affects all family members. Parents of children with type 1 diabetes are always concerned about all aspects of children's life. The aim of this study was to elucidate the process of managing children with diabetes in the family. Materials and Methods: This is a qualitative grounded theory of a doctoral dissertation, which was done on 2016. The 18 participants were selected through purposive and theoretical sampling until data saturation. The main participants in this study included parents, siblings, and children with type 1 diabetes. The data was gathered by semi-structured interviews as well as field notes and memos. Data analysis was done concurrently with data collection in four levels, including data analysis for concept and contex, bringing the process into the analysis, and integration of categories according to Corbin and Struss (2008). Core category appeared at the end of integrated categories. Results: "The family with diabetes in the child's diabetes orbit" as a core category contains the process of managing children with diabetes within the family, which included three main subcategories, including "entering into the diabetes orbit", "movement into the diabetes orbit", and "living into the diabetes orbit". Conclusions: The family through the concept of "The family with diabetes in the child's diabetes orbit "as a main concern of families with diabetes suffering diabetes attempt to select and practicing appropriate strategies and manage diabetes and children with diabetes.

Keywords: Child, diabetes mellitus, type 1, disease management, family, Iran

Introduction

Chronic illnesses that occur at birth or early childhood require special attention during developmental changes and across the life span. Type 1 Diabetes Metllitus (T1DM) accounts for 5–10% of individuals with diabetes. Overall, approximately 80,000 children under 15 yrs are estimated to develop type 1 diabetes annually worldwide.^[1] Diabetes is the chronic illness that affects all family members,^[2] and conquests several facets of family life of children with diabetes.^[3-5]

Nurses along with the parents has a pivotal role in diabetes management within the family. Nurses must use evidence-based knowledge to empower families with the information, skills, and abilities. The nurses as a first-line healthcare providers have a pivotal role in Diabetes care^[6] Nurses have a role in teaching diabetes education according to an individual's needs, and ensuring it is led in a proper path to change behaviors.^[7]

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Concerning the issue of health, the family health is seen as a whole which introduces the family as a unique identity in the health discussions so that the individual health heavily depends on the family health.[8] Diabetes is introduced as one of the research priorities in which addressing the health of families and young people is a focal point to the World Health Organization.^[9] The challenge of living with diabetes can appear as a concern for families from infancy to young adulthood.^[10] Because diabetes requires daily care and attention for a better management.^[11] The Diabetes complications have been intertwined with the everyday life of families.^[12] Children and adolescents diagnosed with T1DM face altered challenges as well as proper metabolic control.^[13,14] A child with diabetes not only challenges his/her own life, but also is a root of changes in the whole family system in the coming years.^[15]

Family roles will change, particularly when health care needs arise due to a chronic health condition for a child within

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the family. Families are crucial partners in promoting the health of their members so that 70–90% of healthcare in the family is offered by its members especially mothers.^[16,17] The father, in addition to having financial responsibilities in the family, attempts to contribute to the care of children with diabetes.^[18] The various factors, including the parents living together, participation in patient care, agreement on the responsibility of family members in the care of the child with diabetes, controlling the self-care activities of the child are effective in yielding a successful management of diabetes.^[19-21] Parents of children with diabetes are expected to manage long-term care of their children.^[22]

Regarding the increasing concern and the requirement of family contribution to the management of diabetes,^[23,24] many studies have been done on the process of care concerning characteristics of the family, as well as cultural, social, and economic aspects affecting diabetes management.^[25] Dozens of studies have examined the concerns and problems families with a child suffering diabetes would face such as hypoglycemia,^[26] stress,^[27] obesity^[28] problems of transition from child to adult^[29] stigma of diabetes^[30] immediate and log-term complication,^[31,32] and other concerns. However, less attention has been paid to the issue that how these concerns are managed effectively by families.

Living with children suffering from diabetes, the family pursues how to better manage the child with T1DM not only in terms of therapeutic aspects,^[33] but also in term of different dimensions of interaction with family and society and improve diabetes management across the lifespan.^[34,35] In this regard, it is essential to know how the family manages its concerns. This multifaceted process can be elucidated by families who have experienced it. Accordingly, in order to highlight all aspects, strategies, and process of managing diabetes and what happens within the family, and also based on the different facet of the Iranian family condition such as health care system, cultural, individual, and social differences this study aims to explain and illustrate this process. This study aimed to investigate the process of managing children with diabetes in the family.

Materials and Methods

This study is a Ph.D. dissertation was done in 2016. The Grounded Theory approach of Corbin and Strauss 2008 was applied to analyze the participants' experiences in order to discover the underlying dimensions that existed in this process.^[36] The participants of the study were mother, father, sister, or brother of children with type 1 diabetes aged under 20 years and one endocrinologist. These participants were recruited from diabetes clinics, societies, and Non-Governmental Organizations (NGOs) in Tehran province. The inclusion criteria contained, children with diabetes living with their parents, the ability to understand and speak Persian language, and a history of diabetes

diagnosis at least greater than one year. The exclusion criteria included: no other chronic comorbidity. Regarding the grounded theory method, first, the participants were selected through purposive sampling. Then, other participants were selected by theoretical sampling based on the research findings until data saturation. Data saturation was achieved with 18 participants. Totally, five interviews with mothers, two with mother and father, three with parents and children with diabetes, one with siblings, and also one interview with an endocrinologist was conducted.

The data was gathered by semi-structured interviews as well as field notes and memos. The interviews were carried out in the form of depth and semi-structured interviews taking place in an environment that participants had a sense of security and peace. Since the parents were worried about their child being away from them during the interviews, they were asked to set the time and place of the interview in a way suitable to their own schedules. The duration of each interview with families was between 45 and 90 min and the meantime for each interview was 69 min. The interviews were recorded if the family permitted.

The interviews with children and adolescents were carried out based on their mental capacity, and their abilities to communicate and to provide information.^[37] Some selected interview questions include: how do you manage the duty of care in daily routine? What are the obstacles and facilitators of controlling children with diabetes? What changes were done to control children with diabetes? What was your reaction in those circumstances? The following probing questions were used for clarifying diabetes management process: Would you exemplify what do you do about "…"? Why do you do "…"? Who was effective on doing "…"? What is the use of doing "…"?

First, the collected data was analyzed word-by-word, line-by-line, and paragraph-by-paragraph in order to generate conceptual codes. These codes are grouped into categories and sub-categories. According to the grounded theory method, data collection, analysis and categorization occur simultaneously through constant comparisons of codes with codes, codes with emerging categories, and categories with categories. Theoretical sampling is used for expanding the categories, merging, and completing categories at the dimensional level for processing the theory.

Accordingly, the Corbin and Strauss approach (2008)^[36] was used. Data analysis was done concurrently with data collection in four levels including analysis data for the concept (use of questioning, constant comparisons, theoretical comparisons and use of techniques such as Close in and Far out, Waving the red flag, and looking at emotions), analysis data for context (attention to the paradigm: condition, action, consequence also using conditional and consequential matrix and micro, meso and macro conditions), bringing the process into the

analysis (use of questioning and conditional relationship guide) and integration of categories in order to create core category (writing memo, using reflective coding matrix writing the line story and drawing the diagram). MAXQDA software version 10 was utilized for data management.

The rigor was established through the criteria cited by Corbin (2008) method and was confirmed by Guba and Lincoln (1998) criteria: Credibility, conformability, transferability, and dependability.[38,39] Data credibility was controlled by participants to determine their certainty regarding the derived concepts. The investigator provided the opportunity to run the research findings consistent with the real-life version of what they have dealt with in the family context. The investigator author made her efforts to present the concepts in a clear and understandable way. At the end of each interview, interviewees were also asked to confirm the main concepts extracted and asked if they tend to review the manuscript of their interview. The investigator did her best to provide sufficient sensitivity to attain the main concepts. Also, data credibility was organized by prolonged engagement with the research environment (about two years) and planning sufficient time for data collection. Data confirmability was done by constant data analysis using some authentic techniques such as member check (providing codes and concepts to one of the parents of children with diabetes and take feedback) (4 persons), peer check (providing codes, categories, and concepts to a physician or a Ph.D. student in nursing) (3 persons), and the researcher attempted to make sure about the trustworthiness of data. Transferability was conducted with the highest variation through sampling [sampling from families with different socioeconomic and educational levels which is reported in Table 1]. Dependability is established using an audit trail (keeping raw data, records, transcript interview, and observation notes from the field) and stepwise replication (one researchers analyze part of the same data separately and compare the results).

In accordance with the grounded theory approach, the investigator, as the main research tool, did her best to collect reliable data by establishing proper communication and creating a proper environment? Due to keeping prolonged contact (above 16 months) with families of children with diabetes, the researcher while focusing on research questions about how the effect of the contextual factors on the manage a child with diabetes, tried to well recognize her knowledge through reflective thinking and writing recalls. As well, at the time of data analysis, the researcher could refer to the recalls to distinguish his viewpoints from the participants' experiences in order to prevent imposing pre-determined assumptions with data.

In fact, ignoring or putting aside such bias is not fully possible but to remove such a limitation, the researcher tried her best to identify all her presumptions and intellectual beliefs prior to the analysis and during transform data to core category through memo writing and being reflexive in the research process.

Ethical considerations

Prior to the study, the researcher clarified the goal and objective of this study, and all potential benefits resulting from participation in the study were explained for the family members. An opportunity of at least 24 h was given to the families to decide upon their participation in the study and subsequently signed the written informed consent. In addition, the assurance was given to the participants that they have the right to escape reflecting on some questions particularly those making them feel upset. They were permitted to stop being interviewed or end up a record over the course of the interview. However, no incidence of stopping while being interviewed or avoiding reflecting on interview questions was observed.

The rights of all participants involved in this study were firmly advocated. The ethical committee of Tehran University of Medical Sciences with approval number of 3548/130/D/9 approves the present study.

Results

The mean age and mean duration of diabetes were 12.3 years and 5.5 years, respectively. The mean age of mothers was 27.40 and fathers were 36.44 years. Other characteristics of 18 participants are given in Table 1. In the microanalysis, 701 open codes were recruited ordered in 41 subcategories, three main categories, and one core category used to describe the process of managing children with T1DM in the family.

Entering into the orbit of diabetes

The category of "entering into the orbit of diabetes" explicates the beginning of a process of managing a child with diabetes in the family. This concept includes three subcategories including "bitter taste of diabetes", "drawing the coordinates of diabetes", and "taking control of diabetes care", more details about this category is available in the published article.^[40]

"The first week was a very difficult for me at hospital... they told me that I should inject insulin, but I dint know... I liked to know more about diabetes, then I decided to go to different classes to learn how to fight against diabetes" (Mother 3).

"I see bodies are not the same; you can't say that a 7 years old diabetic boy should have the same dose as my son does. It depends on physical activities and the food eaten that day" (Mother 7).

The outcomes of entering into the orbit of diabetes is that the family starts to conduct a situation analyses or needs assessment to be prepared and simultaneously begins caregiving. This way, the family gets ready to grasp the reins of diabetes.

	Table 1: Characteristics of participants (n=18)						
	Interviewee	Age of children	Duration of	Age of child	Education of	Ocupation of	
		at the time of	diabetes (year)	at the time of	interviewee	interviewee	
		interview (year)		diagnosis (year)	parents	parents	
1	Mother	11	2	9	Diploma	Employee	
2	Mother	6	2	4	Bachelor	Housewife	
3	Mother and Father	12	5	7	Bachelor	Employee	
					Bachelor	Self-employment	
4	Mother	10	2	8	Bachelor	Housewife	
5	Mother and daughter with diabetes	14	11	3	High school	Housewife	
6	Mother	14	13	1	Diploma	Employee	
7	Mother	8	4	4	Bachelor	Housewife	
8	Mother and Father	10	3	7	Bachelor	Employee	
					Bachelor	Employee	
9	Mother and son with diabetes	18	2	16	High school	Housewife	
10	Mother and daughter with diabetes	24	11	13	Diploma	Employee	
11	Sister and Brother with diabetes	16	3	13	University student	Unemployed	
12	Pediatric endocrinologist	_	_	_	Subspeciality	Associate professor	

Codes	Subcategories	Main category
Tracking diabetes footprint	Riding on the surf of caring	
Diabetes on the shoulders of the primary caregiver		
Intertwined with insulin		
Flattening the table of diabetes		
Diabetes in school bag		
Tendency for a vibrant life		
Searching for alternative medicine		
Spending money wisely		
Adding to the family budgets	Preparing the diabetes backpack	Movement into the orbit of diabete
Diabetes as an interaction point in the family		
Family along with healthcare team		
Seeking support from organizations		
Leaning on the company of others		
Pursuing a superior force		
Age-appropriate care	Moving in the child's pivot	
In accordance with the child's demands		
Secret deal		
Breaking care lines		

Movement into the orbit of diabetes

At this stage, the family fully proceeds to control diabetes. The categories of this stage include "Riding on the surf of caring", "Preparing diabetes backpack", and "Moving in the child's pivot". At this stage, the family has taken the helm of caregiving and rides on the waves of diabetes caring. Considering the fact that the child is also one of the pillars of diabetes care, the family pays more attention to the personal needs of the child with diabetes. What goes into the backpack of the family as they travel in this way may vary based on the unique characteristics and circumstances of the family. A sample of a code, sub categories and categories is presented in Table 2 [see Table 2].

"The test strip is very important for us. When we have money we buy 10 to 12 packages of strip tests, insulin and so on.... Since they are 3 with diabetes... their doctor told us to save for the coming 6 months... We try to always save for the future" (Mother 8).

"I sometimes let him play his own song, because if I say no for everything he doesn't accept my notions anymore... you see if I every time stopped him to eat things he used to like then he wouldn't listen to me any more" (Mother 2).

This category indicates that the family actively gets involved in the caregiving of all aspects of a patient's life and well-being including school, family, and community partnerships. Characteristic of this category include taking control of diabetes care in all dimensions, and providing support and resources for caring, and caregiving with a focus on personal characteristics and needs of the child with diabetes.

Living in the orbit of diabetes

At this stage, the family gets ready for living with diabetes and tries to maintain the family's equilibrium as an entity affected by diabetes. This category includes "Shaping the child with diabetes", "Formation of the family with diabetes", and "The window to the infinite orbit". A sample of code, subcategories, and categories is presented in Table 3.

"When she found that I have to go to work and I can't take care of her while I was at my work then she tried to stand on her own foot. I use to coach what to do ... I controlled her until she became independent" (Mother 6)

"We doubt buy sweets anymore.... we act so that we also have diabetes! We do not eat fried food any more everything is boiled.... After four years of my marriage, my little girl became diabetic..... Almost from the beginning of our marriage we follow a diet. I feel our life is healthier" (Mother 5).

This level is characterized by dressing up the child with the cloth of diabetes as well as planning for a future with diabetes. The outcome of this stage is to identify the intersection between children and diabetes, birth of a diabetic family, and continuing to live in an unceasing way.

Core category The family with diabetes in the child's diabetes orbit

The management of the child with diabetes occurs in three stages, wherein each stage has an order relationship with another stage [Table 4]. However, this doesn't imply that an exact boundary is between the start and end of each stage, but these stages are interconnected and are performed ascendingly by family. Specifically, some of the concepts of the second and third stages may begin to take shape coincidently. In this process, the direction of movement is from "entering into the orbit of diabetes" toward "living in the orbit of diabetes" with no turning back experience. Each family, according to personality traits and family underlying circumstances can undergo this process at different points of time [Figure 1].

Discussion

The process of caring for a child with T1DM is an experience that takes place over time. This is mainly because the family has no previous history of dealing with diabetes, and also diabetes is not like any of the events that have ever been experienced previously by the family. Therefore, the family is unable to use past experiences to control the situation today. This core category encompasses two fundamental concepts, including "Family with diabetes" and "the orbit of child's diabetes".

Family with diabetes

The basic foundation of family living with diabetes is established based on the features of diabetes. Heading in a healthier direction, the family is now concentrated on how to control this situation while maintaining the child's health hand balancing the family and all its members.

The family thinks every day about the needs which should be addressed, and in this way, the family while obtaining

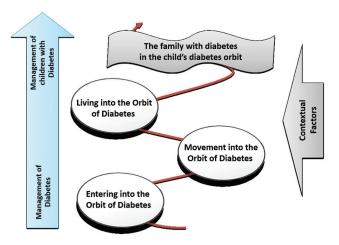


Figure 1: Process of the management of children with diabetes within the family

Table 3: The codes, subcategories, and main category of living into the orbit of diabetes						
Codes	Subcategories	Main category				
Umbrellas of parental supervision	Shaping the child with diabetes					
Empowering the child						
Pedaling along with parents						
Reordering of life	Formation of the family with diabetes					
Establishing diabetes culture		Living into the orbit of diabetes				
Maintain the natural pathway of life						
Alternative caregiver						
Look ahead to the future	The window to the infinite orbit					
Diabetes and ring marriage						
Diabetes and occupation						

Core Category	The family with diabetes in the child's dia	ibetes orbit			
Process	Entering into diabetes orbit	Movement into diabetes obit	Living into diabetes orbit		
Properties	Bitter taste of diabetes diagnosis	Focusing on diabetes and taking	Dressing up the child with the cloth		
	Confronting with the impacts of diabetes	control of care	of diabetes		
	diagnosis on family life	Providing contextual factors for a consistent care	Dressing up the child with the cloth of diabetes		
	To give a meaning of diabetes on self and family	Providing care considering the	Planning for a future with diabetes		
	Attempting to grasp the rein of diabetes care	child's characteristics			
Dimensions	Diabetes rush	Tracking diabetes	Umbrellas of parental supervision		
	The meal behind the food diet ban	Diabetes on the shoulders of the primary caregiver Intertwined with insulin Flattening the table of diabetes Diabetes in school bag	Empowering the child		
	Leakage of money from diabetes split		Pedaling along with parents Reordering of life		
	Diabetes image in the mirror of others				
	Confronting with caring obstacle and		Establishing diabetes culture Maintain the natural pathway of life Alternative caregiver		
	consequences of diabetes				
	To give a meaning of diabetes	Tendency for a vibrant life			
	Keep diabetes hidden	Searching for alternative medicine	Look ahead to the future		
	Being equipped with knowledge and	Spending money wisely	Diabetes and ring marriage		
	expertise	Adding to the family budgets	Diabetes and occupation		
	Grabbing the rein of diabetes Living in the framework of limitations	Diabetes as an interaction point in the family	Diabetes and occupation		
	Diabetes as the main priority	Family along with healthcare team			
	Founding the order at home	Seeking support from organizations			
	r ounding the order at nome	Leaning on the company of others			
		Pursuing a superior force			
		Age-appropriate care			
		In accordance with the child's			
		demands			
		Secret deal			
		Breaking care lines			
Context	Facing with the limitations caused by diabetes	Diabetes is a chronic disease that requires 24-h care coverage	Involving the children in the care		
	Unpleasant image of diabetes in the society	Diabetes Care is challenging for the family at the beginning of the process Diabetes needs social, financial and psychological support for ongoing care	Monitoring child's self-care		
	High costs of treatment		Provision of user-friendly guideline for family members Creation of a well-understood famil living with diabetes Paying attention to all dimensions of diabetes in the family while		
	Imbalanced life				
	Family members, especially parents as the				
	primary diabetes caregivers are				
	Primary caregivers need to have the knowledge, skills, and abilities.	Attention should be paid to children besides focusing on diabetes	searching for new and definitive treatment options		
Outcome	Dealing with a new experience in the life	Full focus on diabetes and its	Identifying the intersection between		
	Feeling the tension and discomfort raised by the incidence of diabetes	management Providing support and making use	children and diabetes Advent of a family living with		
	Need for knowledge of diabetes	of underlying factors to provide a better care Attention should be paid to children besides focusing on diabetes	diabetes		
	Relative understanding of the meaning of		Continuing to live in an unceasing		
	diabetes and care		orbit of child's diabetes.		
	Identifying the weaknesses and failures in the management of diabetes				
	Taking the responsibility for care by family				
	Making the infrastructure required for care responsibilities				

Table 4: Reflective coding matrix in the process of management of children with diabetes in the family Category The family with diabetes in the child's diabetes orbit

relative control of diabetes, pays attention to another component of this composition which is the child himself or herself. A new form of family is then born, where the child and diabetes are interconnected and contextual factors are well taken into account. This family provides care, spending the least energy and tension as possible.

Diabetes self-management occurs in the context of close interpersonal relationships within the family. Parents must rapidly master and teach others about their child's diabetes care, and constantly work to help the child achieve tight blood glucose control.^[35] The result of systematic review of Feldman (2018) showed that parents' intervention in the management of diabetes with children include family restructuring, responsibility-sharing, behavioral contracting, goal setting, and advanced diabetes education.^[41] According to the nurses' roles and abilities, they could promote strengthen healthcare providers and families in diabetes management.^[42] However, Kassai (2015) declared that the nurses have fewer influences in diabetes control in comparison with parents. Nurse-led intervention to improve A1C did not show a significant benefit in adolescents with type 1 diabetes because of lack of power. The result did not explain improvements in A1C control in teenagers by nurse-led intervention.^[43]

The orbit of the child's diabetes

The orbit of diabetes is characterized to be distinctive from that of family. The restrictions and prohibitions associated with this orbit which is more highlighted during the early diagnosis of diabetes and constant care is of the main characteristic of this orbit which requires capacity and consciousness. The orbit of a child's diabetes is a situation where diabetes is intertwined with the personal characteristics and requirements of the child. The direction of movement is forward and the speed of movement depends on family characteristics.

By moving along this orbit, the family attempts to reach to a point where it could create a unity between diabetes and family. Having reached this point, the family arrives at "living in the orbit of diabetes". The family is well informed that the movement in the orbit of diabetes is uninterrupted with the increase of age and years of diabetes diagnosis. Moving along such an orbit with the focus on diabetes is blended with the life of the child with T1DM.

The results of some other studies explain some parts of this process. A study participated by 21 Swedish parents showed that followed by a diabetes diagnosis, the parents lose control of their lives. As a consequence, the concept of taking back control is highlighted.^[44] This concept is similar to "Grabbing the rein of diabetes" in the category of "entering to the diabetes orbit" and "taking control of diabetes care" [Table 4]. To continue in this process, the family thinks about an alternative option of "responsibility sharing". It is similar to "Umbrellas of parental supervision" belong to "Living into diabetes orbit". In addition, one of the subcategories raised in this study is "intensified motherhood" which implies more attention to the child and even more physical presence of the mother. Other subcategory in this process is "justified fatherhood" which leads to greater participation of the father in the child's daily activities. The central concept of "family reconstruction" represents the parents trying to change the everyday life matters after a diagnosis. This process initiates with a "review of the daily routines of the family".^[44] As the results of this study show, some implications from this study are consistent with the concepts of our study, such as "formation of the family with diabetes."

Another study showed that the family member's everyday experiences such as "knowledge and tried experience give skills", "ambivalent parenthood", "stressful daily planning", "fear of losing control", and "private and public concerns" are the main worries of families of diabetic children.^[12] These concepts are confirming our findings such as "Being equipped with knowledge and expertise", "Confronting with caring obstacle and consequences of diabetes" and "Diabetes image in the mirror of others" [Table 4].

One of the main results of Babler et al. study (2016) was the concept of "normalizing". Normalizing was defined as the ability to integrate diabetes into daily life to make diabetes "part of me". Also, the study showed that one of the phases of normalizing was "Figuring it out" which include subcategories: learning to accept diabetes, believing it's possible to manage their diabetes, showing responsibility, and staying on track, and the normalizing task was "accepting the new normal".[45] These findings are according to our study concepts such as "maintain the natural pathway of life", "Reordering of life", and "Establishing diabetes culture". The study of Saylor and et al (2019) in college students in which newly diagnosed diabetes showed that diabetes affects all aspects of life and complicates college living and also college environment affects diabetes management.^[46] One concept in our study was "Diabetes in school bag" it means diabetes Care is challenging for the family and children out of the home.

The result of the study of Bakker and *et al.*, (2019) about Meaning in life experienced by parents of children living with diabetes create the concepts such as normalcy that incorporate the diabetes care plan, empowering their children to successful transition to independent care, positive relationships with their medical team as well as acquiring and sharing diabetes-related knowledge and skills add to the meaning in the life of these parents.^[47] These findings are similar to our study findings such as "Maintain the natural pathway of life", "Diabetes as an interaction point in the family", and "Family along with healthcare team."

Conclusion

The result of this study showed that the management of a child with diabetes takes place in a subsequent order which begins to take shape and be completed within the family. While development within the family, this process is affected by a number of economic and social-cultural as well as healthcare factors where each can serve as facilitators or barriers to this process. The result of this study could enable health care providers to design structure for diabetes management within the family.

Therefore, since nurses have an important role in being involved in diabetes care within the family, it is of great importance to clearly identify their multiple roles in diabetes care special in comparison with parents, to decrease any barriers that prevent them from providing adequate care, and to enhance any facilitators that allow them to provide the best quality care.

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Conflicts of interest

Nothing to declare.

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