

Family Experiences in Supporting Diabetes Self-Management Practice: A Qualitative Study


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ARTICLE INFO

Article history:

Received 22 October 2025

Revised 19 December 2025

Accepted 29 December 2025

Available online

<https://talenta.usu.ac.id/IJNS>

E-ISSN: 2685-7162

How to cite: Tarigan, M., Harahap, S., Nasution, S.Z., Bukit, E.V., Lindarto, D., Silaban, D.F. (2025). Family experiences in supporting diabetes self-management practice: a qualitative study. *Caring: Indonesian Journal of Nursing Science*, 7(2), 259-268.

ABSTRACT

Family participation plays a vital role in the success of diabetes self-management (DSM). In Indonesia, family-centered care is culturally embedded, yet limited research has explored how families experience and interpret their roles in supporting self-management among patients with type 2 diabetes mellitus (T2DM). This study aimed to explore family experiences in supporting diabetes self-management practices among patients with T2DM in Medan, Indonesia. A descriptive phenomenological approach was employed. Twelve family members who cared for T2DM patients at Chairuddin Panusunan Lubis Hospital were recruited using purposive sampling. Data were collected through in-depth interviews and field notes from February to May 2025. Colaizzi's seven-step analysis method guided data analysis to extract significant statements and formulate themes. Credibility was ensured through member checking, dependability via team discussion, and confirmability through audit trails. Five interrelated themes emerged: (1) controlling diet, (2) arranging physical exercise, (3) administering medications, (4) emotional support, and (5) utilization of health care facilities. These themes reflected how families act as emotional motivators, behavioral supervisors, and coordinators of care to strengthen patients' adherence and self-efficacy. Family involvement was not limited to instrumental assistance but extended to emotional reinforcement and facilitation of healthcare access. Family engagement forms the backbone of effective DSM, integrating physical, emotional, and social support. Strengthening family-based interventions is essential to enhance adherence, glycemic control, and quality of life among patients with T2DM.

Keyword: Family Experience, Diabetes Self-Management, Family Support, Qualitative Study, Indonesia



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<https://doi.org/10.32734/ijns.v7i2.23251>

1. Introduction

Diabetes is a serious global problem, occurring when body is unable to produce enough insulin or is unable to use the insulin produced effectively or both. Type 2 diabetes (more than 90%) is much more prevalent than type 1 diabetes. The prevalence of diabetes in adults aged 20–79 years is steadily increasing with an estimated

588.7 million and 852.5 million people in 2024 and 2025, respectively. Indonesia is the fifth highest with an estimated number of 20.4 million in 2024 and is expected to be 28.6 million in 2050 (IDF, 2025).

Diabetes self-management (DSM) must be implemented by diabetic patients to reduce complications (Fadli et al., 2024). DSM can be defined as how a diabetic patient implements self-care that consists of knowledge, attitude, and behaviors to maintain individual health and prevent the onset of diabetes complications. The goal of diabetes self-management is to achieve controlled blood glucose levels through dietary management, regular physical exercise, weight management, adherence to medication, foot care, monitoring of blood glucose levels, and healthy psychosocial coping (Cengiz & Korkmaz, 2023; Chen & Su, 2022; Jiang et al., 2024; Nguyen et al., 2022).

Family plays an important role in providing support to diabetic patients (Effendy et al., 2015). Family support is an act of family acceptance of family members who have a health problem, which consists of 4 supports, namely emotional, instrumental, informational, and appreciation. Moreover, the family is expected to provide support in recovery program at the first time the patient diagnosed with diabetes (Setyoadi et al., 2023). This family support is needed by diabetic patients to carry out daily activities aimed at controlling blood glucose levels (Kristaningrum et al., 2021; Molla et al., 2023). In line with culture in Indonesia, the World Health Organization (WHO) states that families must be involved and play an active role in providing care to patients with chronic diseases such as diabetes (WHO, 2002). Adequate support from the family contributes positively to the goal of the treatment of diabetic patients (Wulandari et al., 2020).

Family support has been shown to be a key factor that determines the success of self-management in diabetic patients, both through improved self-care behaviors, glycemic control, and quality of life. Studies show that active family involvement significantly improves self-management behavioral scores compared to interventions without family support (Diriba et al., 2023; Zhu et al., 2025). Family support strengthens patients' self-efficacy in managing diabetes, as well as increases knowledge and motivation for both patients and family members (Rondhianto et al., 2019; Zhu et al., 2025). Interventions involving families have been shown to reduce HbA1c levels, blood pressure, and body mass index, as well as significantly improve glycemic control, especially in the Asian region (Werfalli et al., 2020; Zhu et al., 2025).

Despite the well-documented importance of family involvement in diabetes self-management, existing research has predominantly focused on quantitative outcomes, such as glycemic control, self-care adherence, and clinical indicators (Zhu et al., 2025). While these studies demonstrate the effectiveness of family support, they provide limited insight into how families experience, interpret, and negotiate their roles in supporting daily self-management practices. In particular, the subjective meanings, emotional challenges, and contextual strategies employed by family caregivers remain insufficiently explored. Moreover, most existing qualitative studies on family support in diabetes management have been conducted in Western or high-income settings, where healthcare systems, family structures, and cultural norms differ substantially from those in low- and middle-income countries. In collectivist societies such as Indonesia, family members often assume primary responsibility for long-term caregiving, decision-making, and treatment supervision.

Without an in-depth understanding of family experiences, diabetes interventions may remain overly patient-centered and fail to adequately incorporate family dynamics, caregiving burdens, and culturally grounded support mechanisms (Mamatsharaga et al., 2022). This gap is particularly concerning given the rapidly increasing prevalence of type 2 diabetes mellitus in Indonesia, where family members often function as the primary extension of the healthcare system in daily disease management. Therefore, understanding family experiences in providing supportive self-management practices is needed as a basis for designing diabetes management from a family perspective.

However, research on exploring family experiences in providing support for self-management practice has not yet been adequately explored through qualitative phenomenological research in North Sumatra, Indonesia. Several descriptive phenomenological studies have been conducted in Indonesia to gain an in-depth understanding of family experiences in caring for family members with diabetes. These include a study in Depok, West Java, which explored the meaning of family experiences in caring for older adults with diabetes (Sofwan Sofwan, 2024),); a study in Delitua, North Sumatra, which examined family experiences in caring for patients with diabetic foot ulcers at home (Ginting et al., 2021); and a study in Bukittinggi, West Sumatra, which explored family experiences in providing support for patients with diabetes (Krismayenti et al., 2022). Therefore, this study aims to examine the experiences of family in providing self-management practice support in patients diagnosed with type 2 diabetes.

2. Methods

This study used a descriptive phenomenological design. Phenomenological research aims to capture the inner experiences and personal perspectives of those who directly experience a phenomenon (Zhang et al., 2024). A phenomenological approach is highly aligned with the context of diabetes self-management, which largely takes place in the home and is strongly shaped by patient–family relationships. The role of the family in DSM extends beyond merely “performing tasks” such as preparing meals or reminding patients to take medication; it also involves values, a sense of responsibility, stress, and the construction of caregiver identity (Newson et al., 2025).

Participants in this study were family members who cared for patients diagnosed with type 2 diabetes. Participants were recruited at the Chairuddin Panusunan Lubis Hospital, a teaching hospital of the Universitas Sumatera Utara, Medan, Indonesia. According to Bustamante and Martinez (2025), the recommended number of participants in a phenomenological study is a minimum of six and a maximum of 20 people. Therefore, in this study, a total of 12 of participants were recruited using the purposive sampling method. The inclusion criteria were able to speak fluently in Indonesian language, willing to volunteer to be a participant, and have been caring for diabetic patients for at least 2 years.

The data collection tools in this study were demographic characteristics questionnaire, interview guides, field notes, and a voice recorder. The demographic data questionnaire consisted of age, gender, education level, and relationship with participants with diabetic patients. The interview guidelines were developed based on an extensive review of the literature on diabetes self-management and family support, existing qualitative studies, and DSM frameworks. The researcher as the main instrument, used several follow-up questions to dig deeper information from the participants. A field notes were used as written records of what the researcher heard, saw, experienced, thought during the data collection process. A voice recorder, specifically a Samsung A15 smartphone, was used to audio-record all interview conversations.

Data collection was carried out from February to May 2025, after a research permit and passed the ethics test (Research Ethics Approval No: 162/KEPK/USU/2025) were obtained. All interviews were conducted face-to-face in a private and quiet area of the outpatient clinic at Chairuddin Panusunan Lubis Hospital. This approach allowed the researcher to establish rapport, observe non-verbal cues, and gain a deeper understanding of participants’ expressions and emotions during the interviews. Each interview was carried out individually, lasted approximately 45–60 minutes, and was audio-recorded with participants’ consent. Data saturation was achieved when consecutive interviews produced no new themes or meanings. After the tenth interview, recurring patterns were consistently observed, and interviews 11 and 12 only confirmed existing themes. Field notes further supported saturation by documenting repetitive behaviors and emotional expressions, indicating that sufficient depth and breadth of data had been obtained.

Data analysis was following the Colaizzi method (Sanders, 2003). The first step was acquiring a sense of each transcript, where the researcher listened to the recordings 3 to 4 times and read the transcript 4 to 5 occasions. The second step was extracting significant statements, where the researcher reads and re-reads transcripts to identify and underline participants’ specific statements about diabetes self-management practices. The third step is the formulation of meanings. At this stage, the researcher formulates significant statements into more general statements. The fourth step is organizing formulated meanings into clusters of themes, where researchers group formulated meanings into clusters of themes. The fifth step is exhaustively describing the investigated phenomenon. At this stage, the researchers integrate all the results of ideas about the phenomenon into an exhaustive description. The sixth step is to describe the fundamental structure of the phenomenon. At this stage, the researcher organizes all themes and sub-themes into a structured incidental phenomenon. The seventh step is returning to the participants, which is the researcher validating by sending the results of data analysis to the participants to ensure that the phenomenon that has been written is a representation of the experience they experienced. An example of the data analysis for participant 10 is displayed in Table 1.

Table 1 Example of data analysis process

Theme	Theme-cluster	Formulated meaning	Significant statement
Controlling diet	Efforts to control patients’ eating habits	Unable to control food intake consistently	“I’m not able to control the food because it’s impossible for me to manage everything she eats. So clearly, controlling her diet is difficult.”
		Patients frequently eat outside scheduled meals	“Sometimes, right after finishing a meal, she eats bread again. She also regularly eats fruit, like oranges.”

Table 1 Continued

Theme	Theme-cluster	Formulated meaning	Significant statement
		Does not restrict food completely but encourages portion limitation	“It’s not necessary to eat or drink everything. Just enough rice is fine. If you want sweet tea, just drink a little—it’s okay, half a glass. Eat half, then walk for a while, I tell her.”
		Unable to continuously accompany the patient in monitoring food and beverage intake	“If I leave her alone, it’s impossible for me to watch her all the time. Suddenly she orders coffee, and I see that the coffee contains sugar.”
	Managing the type and schedule of the patient’s diet	Assisting in regulating meal portions	“I do help with arranging the meals.”
		Meals are prepared by the patient with predetermined portions	“For daily meals, she prepares them by herself. At night, I determine the portions. During the day, since we eat together, I bring rice from home with portions that I’ve already determined.”
		Portion control is performed by the caregiver	“The portion is about one ladle spoon, maybe one and a half. For side dishes, there is usually fish and meat, but the fish is often fried and cooked with coconut milk.”
		Difficulty controlling restricted foods (fat and sugar)	“What is difficult to control is fat, especially from coconut milk, and sugar. She also often eats sweet bread and cakes bought from stores, those with sugar and chocolate.”
		Consuming a low-sugar breakfast	“For breakfast, she eats crackers, and the drink is palm sugar water.”
		Night-time snacking habits persist	“Sometimes at night there are cakes, such as festive cookies or sweet dry bread sold in shops with chocolate, and these are still often eaten.”

Trustworthiness

Regarding credibility, member checking is carried out after the findings are obtained. Member checking was carried out via a smartphone between the researcher and the participant. For dependability, the researchers conduct several discussion sessions with the research team to identify and ensure the data collection and analysis process is in accordance with the research objectives and framework. Regarding confirmability, this stage is carried out by having discussions with the research team when determining the theme of the research results and reading similar research articles. For transferability, the demographic data of the participants and the location of the study are written in detail, so that the reader can assess the accuracy of the way the researcher transfers the results of his research to the readers and other researchers.

3. Results

The demographic characteristics of the twelve participants are displayed in Table 1. The participants’ ages ranged from 25 to 69 years. Most participants were female ($n = 7$), while five participants were male. In terms of educational background, four participants held a bachelor’s degree, five graduated from senior high school, and one completed junior high school. Regarding the relationship with the patient, participants comprised five spouses (wives or husbands) and seven adult children.

Table 2 The characteristics of participants

Participant	Age (Years)	Gender	Education Level	Relation to Patient
1	32	Female	Bachelor	Child
2	45	Female	Senior High School	Wife
3	54	Female	Senior High School	Wife
4	62	Male	Bachelor	Husband

Table 2 Continued

Participant	Age (Years)	Gender	Education Level	Relation to Patient
5	41	Female	Bachelor	Child
6	65	Male	Bachelor	Husband
7	28	Female	Junior High School	Child
8	55	Female	Bachelor	Wife
9	25	Female	Senior High School	Child
10	69	Male	Senior High School	Husband
11	66	Male	Bachelor	Husband
12	26	Male	Senior High School	Child

Table 3 Theme and Theme Cluster

Theme	Theme Cluster
Controlling diet	<ol style="list-style-type: none"> 1. Preparing meals 2. Reminds of foods to avoid 3. Limiting food intake
Arranging physical exercise	<ol style="list-style-type: none"> 1. Initiating, encouraging, and supervising physical exercise 2. Physical exercises guided by experts
Administering medications	<ol style="list-style-type: none"> 1. Injecting injectable drugs 2. Independently manage the dose of medication when blood sugar levels rise 3. Preparing oral medications in a special way
Emotional support	<ol style="list-style-type: none"> 1. Provide encouragement and advice 2. Advocate patience when patients are stressed or emotional 3. Reminding patients to control emotions
Utilization of health care facilities	<ol style="list-style-type: none"> 1. Always accompany patients to medical facilities for treatment 2. Utilize health services if there are complaints 3. Inviting patients to take health control in the outpatient unit

The findings of this qualitative study revealed five main themes reflecting the family experience in supporting diabetes self-management practice.

3.1. Controlling diet

This theme highlights the family's role as gatekeepers of dietary adherence, reflecting a collaborative effort to maintain nutritional balance and prevent complications. Families were actively involved in regulating the patients' dietary habits to prevent blood glucose elevation. They demonstrated commitment by selecting suitable food ingredients, preparing healthy meals, determining appropriate portion sizes, and ensuring that patients avoided foods containing sugar or other dietary restrictions. This involvement reflects a sense of responsibility in controlling the patient's daily food intake as part of glycemic management. One participant expressed this dedication:

"I prepare special meals with red rice, always steamed. I don't use egg yolks every day; I buy only the whites. Fish is either steamed or cooked in asam padeh without coconut milk... So, my husband's meals are special and different from ours." (P8)

Families also took an active role in reminding patients to limit sweet foods or replace them with diabetic-friendly alternatives. As another participant mentioned:

"We reduce sugar intake and replace it with diabetic milk. When visiting others, we avoid drinking sweet tea. We also reduce rice portions." (P11)

3.2. Arranging physical exercise

This theme indicate that the family's encouragement and involvement in exercise routines are instrumental in sustaining the patient's physical well-being and promoting glycemic control. Encouraging and maintaining physical activity emerged as another important form of family support. Family members motivated patients to engage in daily exercise, such as morning walks or sunbathing, and provided companionship to ensure

compliance. Their presence served as both a reminder and a source of motivation. For example, one participant stated:

“If he isn’t accompanied, he won’t go for a morning walk. Sometimes his daughter accompanies him.” (P6)

In addition, some families sought professional assistance, such as physiotherapy, to help patients perform safe and effective physical activities:

“For physical exercise, he receives physiotherapy twice a week, each session lasting about one and a half hours.” (P11)

3.3. Administering medications

This theme illustrates that family involvement in medication administration is a crucial aspect of diabetes care, ensuring consistent treatment and preventing glycemic fluctuations. Families played an essential role in ensuring medication adherence and safety, particularly among elderly patients who were dependent on others for insulin injections or oral medications. Some family members assumed full responsibility for preparing and administering the medication, while others encouraged patients to learn self-injection for greater independence. As one caregiver explained:

“I’m the one who gives the injections. I told her to try injecting herself in the stomach because I’m busy, but she said, ‘I can’t do it.’” (P1)

Another participant described similar experiences:

“I prepare and inject the insulin myself, changing the needle each time... He’s been on insulin for six months; before that, it was only glibenclamide.” (P10)

Medication management was not limited to injections; family members also prepared oral medications to ensure adherence. As one participant mentioned:

“If I go out and don’t prepare his oral medication, he won’t take it. He’ll only take it if I’ve already set it out for him.” (P3)

3.4. Emotional support

Emotional support was a recurring theme that underscored the importance of psychological and motivational assistance in diabetes self-management. Caregivers provided comfort, reassurance, and encouragement to help patients cope with emotional distress, anxiety, or frustration related to their condition. They promoted optimism and patience, helping patients maintain emotional stability during treatment. Such support helps strengthen the patient’s psychological resilience, fosters motivation to follow treatment plans, and reduces the emotional burden of living with diabetes.

One participant explained:

“When he was first told he had diabetes, I told him not to think too much about it. ‘We encourage each other and avoid arguments.’” (P2)

Another participant reinforced the importance of maintaining a positive attitude:

“I try to keep my mother’s spirits up, always telling her to stay positive. I tell her she can recover—it’s not impossible.” (P12)

3.5. Utilization of health care facilities

The final theme reflects how families facilitated access to and utilization of health care services. Family members often accompanied patients during outpatient visits, laboratory tests, and medical consultations. This accompaniment demonstrated their responsibility and concern for ensuring continuity of care and adherence to scheduled appointments. These findings highlight that families not only provide logistical and emotional support but also play a vital role in facilitating access to healthcare resources necessary for optimal diabetes management. As one participant described:

“I’m the one who always accompanies my mother to the doctor and hospital. I want to hear the doctor’s explanation myself. I feel it’s my responsibility to take her for check-ups.” (P10)

Other families sought care at local community health centers whenever symptoms worsened or when the patient felt weak:

“We go to the community health center to check her blood sugar whenever she feels weak or unwell.” (P12)

4. Discussion

The first theme was controlling diet. Family involvement is very important in regulating the diet of diabetic patients. Families can help prepare meals as recommended by the doctor, remind them of meal schedules, and supervise the patient's food consumption. This involvement directly improves dietary adherence and blood sugar control (Dwi et al., 2024; Hu et al., 2021). In addition, the family plays a role in seeking information related to the diabetic diet, accompanying the patient during consultations, and helping to understand the importance of dietary arrangements (Busebaia et al., 2023). Nevertheless, in some cultures, eating together and sharing food have become an important part of social life. Dietary restrictions can cause feelings of isolation or discomfort, both for the patient and the family, so that the family sometimes succumbs to the patient's wishes in order to maintain harmony (Kurnia & Yulia, 2021; Li-Geng et al., 2020).

The second theme was arranging physical exercise. Family support has proven to be very important in encouraging physical activity of diabetic patients. Families that provide encouragement, remind patients of exercise schedules, and motivate patients to stay physically active, have been shown to increase patient adherence to physical activity (Ananda et al., 2020; Lim et al., 2020). Exercising with family members or getting direct support (e.g., accompanied by a walk) increases the likelihood of patients engaging in regular physical activity (Lim et al., 2020; Tariq et al., 2022). Families who have an active culture or habits, such as frequent discussions about the importance of exercise and making physical activity part of the family routine, can be role models and drivers for diabetics (Ahmad Hatib et al., 2025; Lim et al., 2020). Families who help plan physical activity, provide time, and facilitate patient needs (e.g., preparing exercise equipment or scheduling) also play an important role (Trisnadewi et al., 2025).

The third theme was administering medications. Family involvement plays a major role in improving treatment adherence for diabetic patients. The family provides encouragement, motivation, reminds the schedule of taking medication, helps take medication, and accompanies the patient in undergoing therapy (Hilyah et al., 2025; Mphasha et al., 2022). Families are involved in decision-making, help monitor compliance, and participate in family-based education and interventions (Poonprapai et al., 2022; Yusra & Waluyo, 2022). Families who are educated about diabetes are better able to support patients in carrying out treatment on a regular basis (Busebaia et al., 2023).

The fourth theme was emotional support. Emotional support from family has proven to play a crucial role in maintaining the psychological stability of diabetic patients. Family support increases patients' confidence in managing diabetes, leading to improved emotional well-being and better self-care behaviors (Villaécija et al., 2023). Family social and emotional support significantly reduces the risk of severe psychological distress and depression in diabetic patients, both adults and the elderly (Bao, 2021; Huang et al., 2024). Family involvement in diabetes care improves patients' quality of life, helps them adapt to lifestyle changes, and prevents complications (Mphasha et al., 2022; Villaécija et al., 2023).

The last theme was utilization of health care facilities. Family involvement is very influential in ensuring that diabetic patients receive ongoing care. Families who actively support patients, such as reminding control schedules and accompanying them to health facilities, have been shown to increase patient compliance in conducting regular follow-up visits (Busebaia et al., 2023; Veronika, 2024). A study at the Pratama Clinic of the Jatibening Medical Center, Indonesia found a significant relationship between family support and adherence to diabetic patients in routine control. Patients who receive more family support attend control visits, which is important for preventing complications and managing the disease optimally (Jatibening, 2024). Research at the Cilegon general hospital, Indonesia, also showed that type 2 diabetes patients who received good family support, tended to be more obedient in undergoing treatment and medical control (Jaya et al., 2024).

This study has several limitations. First, the limited number of participants—only twelve individuals—may restrict the generalizability of the findings to a broader population. Second, the processes of data collection and analysis rely heavily on the researcher's interpretation, meaning that the potential for subjectivity cannot be entirely eliminated. Third, the data were collected at a single point in time; therefore, this study was unable to capture longitudinal changes in participants' experiences or perspectives.

5. Conclusion

This qualitative study revealed that family involvement plays a pivotal and multidimensional role in supporting diabetes self-management (DSM) among individuals with type 2 diabetes mellitus. Through five interconnected aspects—dietary regulation, encouragement of physical exercise, medication supervision, emotional support, and facilitation of healthcare access—families serve as both emotional anchors and

behavioral regulators who strengthen patients' adherence and self-efficacy. These findings emphasize that DSM success is not solely dependent on individual patient efforts but also on the synergy between family engagement and healthcare guidance. Therefore, nursing practice should integrate family-centered strategies to empower caregivers, enhance patient autonomy, and foster sustainable self-care behaviors, ultimately improving glycemic control and quality of life among people with diabetes.

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