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## Family Caregivers' Experiences in Caring for Patients with Diabetes Mellitus: A Phenomenological Study

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### Abstract

Patients with diabetes mellitus (DM) require sustained caregiving support from their families. Family caregivers play a pivotal role in supporting blood glucose control and treatment adherence among patients with DM. An in-depth understanding of caregiver experiences is needed to develop precisely targeted family nursing interventions. The study aimed to identify the experiences of family caregivers in providing care for patients with DM in the community. A phenomenological design was employed. Six caregivers of patients with DM enrolled in the Chronic Disease Management Program through purposive sampling. Data were collected through semi-structured in-depth interviews until data saturation was achieved and were analyzed using Colaizzi's seven-step technique. Five major themes emerged: (1) understanding of diabetes based on patient symptoms and causes; (2) home-based care efforts for patients with DM; (3) barriers experienced by caregivers; (4) caregiving motivation grounded in religious devotion and affection; and (5) ease of obtaining care-related information from health workers. The essential structure of the experience centred on caregiving as an expression of family obligation, affection, and spiritual devotion. Family caregivers carry out their caregiving roles on the basis of obligation, affection, and spiritual values. Structured and well-planned family education programs are needed to optimize the caregiver role in DM control.

**Keywords:** caregiver, diabetes mellitus, patient care, phenomenology, family support

## Pengalaman Keluarga dalam Merawat Pasien Diabetes Melitus: Sebuah Studi Fenomenologi

### Abstrak

Pasien diabetes melitus (DM) memerlukan dukungan perawatan dari keluarga secara berkelanjutan. Caregiver keluarga berperan penting dalam membantu pengendalian kadar gula darah dan kepatuhan pengobatan pasien DM. Pemahaman mendalam tentang pengalaman caregiver dibutuhkan untuk mengembangkan intervensi keperawatan keluarga yang tepat sasaran. Tujuan penelitian ini adalah mengidentifikasi pengalaman caregiver keluarga dalam memberikan perawatan kepada pasien DM di komunitas. Penelitian menggunakan desain fenomenologi. Partisipan berjumlah enam orang caregiver pasien DM, dipilih secara purposive sampling. Data dikumpulkan melalui wawancara mendalam semi terstruktur hingga tercapai kejenuhan data dan dianalisis menggunakan teknik tujuh langkah Colaizzi. Lima tema utama ditemukan: (1) pemahaman diabetes berdasarkan gejala dan penyebab pasien DM; (2) upaya perawatan pasien DM di rumah; (3) hambatan yang dialami caregiver; (4) motivasi merawat pasien DM berdasarkan ibadah dan kasih sayang; serta (5) kemudahan memperoleh informasi perawatan dari tenaga kesehatan. Struktur esensial pengalaman berpusat pada perawatan sebagai ekspresi kewajiban keluarga, kasih sayang, dan pengabdian spiritual. Caregiver keluarga menjalankan peran perawatan atas dasar kewajiban, kasih sayang, dan nilai spiritual. Program edukasi keluarga yang terstruktur dan terencana diperlukan untuk mengoptimalkan peran caregiver dalam pengendalian DM.

**Kata Kunci:** caregiver, diabetes melitus, perawatan pasien, fenomenologi, dukungan keluarga

## Introduction

Diabetes mellitus (DM) is a chronic disease whose prevalence continues to rise both globally and nationally. According to the International Diabetes Federation (IDF) 10th edition, 537 million adults aged 20-79 years were living with diabetes worldwide, a figure projected to reach 783 million by 2045 (International Diabetes Federation, 2021). Based on the 2023 Indonesian Health Survey, the prevalence of DM among the population aged 15 years and above measured through blood glucose testing reached 11.7%, an increase from 10.9% in the 2018 Basic Health Research (Kementerian Kesehatan Republik Indonesia, 2023). In West Java, the number of people with DM was recorded at 156,977 (1.7%), while in Bandung City there were 45,430 cases with 507 DM-related deaths in 2022 (Dinas Kesehatan Kota Bandung, 2022).

Unmanaged DM complications can lead to macrovascular disorders (cardiac, cerebral, and peripheral vascular) and microvascular disorders (nephropathy, retinopathy, neuropathy) that seriously affect patients' quality of life (Perkumpulan Endokrinologi Indonesia, 2021). DM control requires a multidimensional approach encompassing education, medical nutrition therapy, physical exercise, pharmacological therapy, and self-monitoring of blood glucose, consistent with the five-pillar guidelines of PERKENI (Perkumpulan Endokrinologi Indonesia, 2021). Successful DM control depends not only on patient adherence but also on the active involvement of the family as the primary support system (Tarigan et al., 2025).

A family caregiver is a family member who actively assists the patient with DM in dietary management, medication administration, accompaniment to health facilities, and emotional support. Friedman (2014) asserts that when one family member becomes ill, the entire family life cycle is affected. The family has five basic functions, including the health care function. Family health tasks comprise recognizing health problems, making decisions, providing care, modifying the environment, and utilizing health facilities (Friedman, 2014).

A study by Ananda et al. (2020) reported a significant relationship between family support and the activeness of patients with DM participating in Prolanis. Jamiat and Salami (2024) likewise

reported a meaningful relationship between the performance of family health tasks and blood glucose stability in patients with DM. These findings indicate that the caregiver role is a determinant factor in community-based DM management (Sofwan, 2024; Siregar et al., 2025).

Despite this evidence, qualitative insight into the caregiving experience itself remains scarce. Existing phenomenological and qualitative studies in Indonesia have concentrated primarily on patients' own lived experiences, such as self-management among patients with diabetic neuropathy (Saltar et al., 2025), or on family experiences in other settings and populations, such as families caring for elderly people with DM (Sofwan, 2024) and family members of patients with type 2 DM in Medan (Tarigan et al., 2025). To the best of the authors' knowledge, no published phenomenological study has explored the experiences of family caregivers of Prolanis participants at the primary health care level in Bandung, particularly in a context where a substantial proportion of participants continue to experience poor glycemic control despite program enrollment. The Kujangsari Primary Health Center was therefore selected as the research setting because it hosts a Prolanis cohort of 64 participants with DM, of whom 22 participants still experienced elevated blood glucose levels, and because the Prolanis coordinator reported that the caregiver role had not been optimal. Understanding how caregivers in this specific context experience and give meaning to their role is essential for designing family nursing interventions that are precisely targeted to local needs.

Therefore, this study aimed to identify the experiences of caregivers in providing care for patients with DM within their families.

## Methods

### Research Design

This study used a qualitative approach with a descriptive phenomenological design. This design was selected because it enables researchers to explore and understand the meaning of participants' lived experiences in depth, as recommended by Creswell and Poth (2018) for studies focusing on real-life phenomena experienced by individuals. The study is reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) 32-item

checklist (Tong et al., 2007), which is provided as Supplementary File 1.

The interviews were conducted directly by the researchers, who hold a specialist background in community nursing (Sp.Kep.Kom), teach nursing at the university level, and have experience in qualitative research. The researchers' interest in family caregiving arises from their community nursing practice background; potential assumptions related to this background were identified and set aside through the bracketing procedures described in Section 2.4. Participants were informed that the study aimed to explore family caregivers' experiences in caring for patients with DM and that participation was entirely voluntary.

### **Setting and Participants**

The study was conducted at the Kujangsari Primary Health Center, Bandung City, West Java, in 2024-2025. The population comprised all caregivers of patients with DM participating in Prolanis at the Kujangsari Primary Health Center (n=64). Purposive sampling was used based on the following inclusion criteria: (1) being a member of the nuclear family serving as the primary caregiver; (2) the patient with DM under their care being an active Prolanis participant; and (3) willingness to participate and to sign informed consent. The number of participants was six, consistent with the principle of data saturation in phenomenological research (Creswell & Poth, 2018). Data collection was stopped after the sixth interview because no new significant statements, categories, or themes were emerging, indicating that data saturation had been achieved.

### **Data Collection**

Data were collected through semi-structured in-depth interviews using an interview guide and an audio recorder. Participants were approached face-to-face through the Prolanis coordinator of the primary health center. The interviews were conducted at a private location agreed with each participant (the participant's home or the primary health center), with no other persons present, and field notes were made during and after each interview. All eligible caregivers who were invited agreed to participate, and there were no drop-outs. The interview guide was developed by the research team based on the study objectives and the literature and covered five domains: understanding

of DM, home-based care efforts, barriers experienced, caregiving motivation, and access to information. The guide is provided in Appendix 1. Each interview session lasted between 45 and 90 minutes. All recordings were transcribed verbatim. The interviews were conducted in Indonesian. The verbatim transcripts were translated into English by the research team, and the accuracy of the translations was verified through back-translation to preserve the original meaning of the participants' statements. Data validity was ensured through member checking (returning transcripts to participants for verification) and triangulation with members of the research team.

### **Bracketing**

To fulfil the phenomenological requirement of bracketing, all members of the research team set aside their prior assumptions, hypotheses, and experiences related to family caregiving for patients with DM before data collection and analysis began. Bracketing was operationalized through pre-interview reflective discussions, in which the researchers articulated and documented their preconceptions in reflective journals, and through continuous reflexivity throughout the analysis. Any pre-understanding that emerged during the study was recorded and discussed in team meetings to prevent it from influencing the interpretation of participants' meanings.

### **Data Management and Confidentiality**

All audio recordings and transcripts were stored on a password-protected, encrypted device accessible only to the research team. During transcription, all identifying information (names, places, and dates) was removed or replaced with participant codes (P1-P6). No personal identifiers were recorded in the field notes. The data will be retained for five years after publication, after which all recordings and transcripts will be permanently deleted. Data management and coding were carried out manually following Colaizzi's seven-step technique; no qualitative analysis software was used.

### **Data Analysis**

Data analysis used Colaizzi's seven-step technique, comprising: (1) reading all transcripts to obtain an overall impression; (2) extracting significant statements; (3) formulating meanings from each statement; (4) organizing meanings into

theme clusters; (5) integrating the results into a comprehensive description; (6) formulating the essential structure of the phenomenon; and (7) validating the findings with participants (Creswell & Poth, 2018).

In practice, each transcript was read repeatedly to obtain an overall sense of each participant's experience. Significant statements directly relevant to the caregiving experience were then extracted and coded independently by the members of the research team. Formulated meanings were derived from each significant statement, compared across transcripts, and clustered into categories. Through iterative team discussion, related categories were consolidated into sub-themes and subsequently into the five major themes; the complete analytical pathway (five themes, 11 categories, and 22 sub-themes) is presented in Table 2. All coding decisions were documented in an audit trail. Disagreements between researchers regarding codes or interpretations were resolved through consensus meetings in which the relevant transcript passages were re-read and discussed until agreement was reached; no disagreements remained unresolved. The final themes and their supporting quotations were returned to the participants for validation (member checking).

### Trustworthiness

Trustworthiness was addressed using the criteria of credibility, dependability, confirmability, and transferability. Credibility was ensured through prolonged engagement with participants during the interviews, member checking (transcripts and theme summaries were returned to participants for verification), and triangulation among members of the research team, who analyzed the data independently and compared their interpretations. Dependability was supported by a documented audit trail covering every step from raw data to the final themes and by consensus-based coding. Confirmability was

strengthened through bracketing, reflexive journals, and the audit trail, which allows the findings to be traced back to the original data. Transferability was facilitated through thick description of the participants, the setting, and the caregiving context so that readers can judge the applicability of the findings to other settings.

### Ethical Considerations

This study was approved by the Research Ethics Committee Universitas Aisyiyah Bandung No :1309/KEP. 01/UNISA-BANDUNG/VI/2025 date of 6 Juni 2025. All participants received written and verbal information about the study, including an explanation of the audio recording procedure, and signed written informed consent prior to the interviews. Participants were informed of their right to withdraw from the study at any time without any consequence. Participant identities were kept confidential using the codes P1-P6.

### Result and Discussion

#### Participant Characteristics

The participants comprised six caregivers. Half of the caregivers were older than 60 years of age (50%), the majority were female (66.7%), half had completed junior high school (50%), and two-thirds had been caregivers for 6 to 10 years (66.7%). Most participants were homemakers (66.7%). The caregivers' relationships to the patients are presented in Table 1 and comprised wives, husbands, and adult children of the patients.

#### Themes of the Study Findings

Data analysis using Colaizzi's technique yielded five major themes derived from 22 sub-themes and 11 categories, as presented in Table 2, which sets out the full analytical pathway from categories and sub-themes to themes, together with representative participant quotations.

**Table 1. Characteristics of Study Participants (n=6)**

| No | Code | Age (yr) | Sex    | Education          | Occupation | Caregiving duration | Relationship to the patient |
|----|------|----------|--------|--------------------|------------|---------------------|-----------------------------|
| 1  | P1   | 55       | Female | Junior high school | Homemaker  | 5 years             | Daughter                    |
| 2  | P2   | 48       | Female | Bachelor's degree  | Homemaker  | 6 years             | Wife                        |

| No | Code | Age (yr) | Sex    | Education          | Occupation     | Caregiving duration | Relationship to the patient |
|----|------|----------|--------|--------------------|----------------|---------------------|-----------------------------|
| 3  | P3   | 31       | Female | Senior high school | Homemaker      | 8 years             | Wife                        |
| 4  | P4   | 61       | Male   | Senior high school | Private sector | 2 years             | Son                         |
| 5  | P5   | 62       | Female | Junior high school | Homemaker      | 10 years            | Daughter                    |
| 6  | P6   | 65       | Male   | Junior high school | Laborer        | 8 years             | Husband                     |

**Table 2. Analytical Pathway: Themes, Categories, Sub-themes, and Representative Quotations**

| Theme                                                                          | Category                            | Sub-themes                                                                                                                                                                                      | Representative quotation                                                                                                             |
|--------------------------------------------------------------------------------|-------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------|
| <b>Theme 1: Understanding of diabetes based on patient symptoms and causes</b> | 1.1 Recognition of initial symptoms | (1) Sudden onset of severe symptoms leading to first diagnosis<br>(2) Classic hyperglycemia symptoms (polyuria, polydipsia, drowsiness)<br>(3) Limb disturbances (numbness, herpes-like wounds) | "my mother kept vomiting on the road, then fainted... her blood sugar turned out to be 480" (P1)                                     |
|                                                                                | 1.2 Perceived causes of diabetes    | (4) Dietary pattern high in sugar and simple carbohydrates<br>(5) Lack of physical activity<br>(6) Unknown cause                                                                                | "The cause is from food, like rice. Now I give her brown rice..." (P3)                                                               |
|                                                                                | 1.3 Awareness of complications      | (7) Partial awareness and unawareness of complications                                                                                                                                          | (Described narratively in Theme 1; participants varied from naming cardiac, ocular, and neurological complications to being unaware) |
| <b>Theme 2: Home-based care efforts for patients with DM</b>                   | 2.1 Daily monitoring                | (8) Medication reminders and administration<br>(9) Monitoring and regulating dietary patterns<br>(10) Physical activity reminders (walking, sunbathing)                                         | "I am the one who gives the medication: morning, noon, and before bed." (P3)                                                         |

| Theme                                                                              | Category                          | Sub-themes                                                                                                       | Representative quotation                                                                                    |
|------------------------------------------------------------------------------------|-----------------------------------|------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------|
| <b>Theme 3: Barriers experienced by caregivers</b>                                 | 2.2 Preventive and emergency care | (11) Periodic inspection of foot wounds<br>(12) Management of emergency conditions (referral to hospital)        | "We took him straight to the hospital... He was in the ICU for three days." (P5)                            |
|                                                                                    | 3.1 Psychological barriers        | (13) Physical fatigue<br>(14) Emotional stress (annoyance, anger)                                                | "There is fatigue. But what can I do? Caring for the sick requires strength." (P3)                          |
|                                                                                    | 3.2 Protective factors            | (15) Patient independence, established routines, and national health insurance (BPJS Kesehatan) coverage         | (Described narratively in Theme 3)                                                                          |
| <b>Theme 4: Motivation for caring for patients with DM: devotion and affection</b> | 4.1 Family-based motivation       | (16) Obligation based on the family role (husband, wife, child)<br>(17) Affection and mutual care                | "Caring is a wife's duty when her husband is ill." (P1, P3)                                                 |
|                                                                                    | 4.2 Spiritual motivation          | (18) Caring as an act of worship (ibadah)                                                                        | "I simply treat it as worship. We just help one another now that we are old." (P5)                          |
| <b>Theme 5: Ease of obtaining DM care information from health workers</b>          | 5.1 Facility-based information    | (19) Clear and understandable education through Prolanis<br>(20) Friendly and comfortable health worker services | "The primary health center is helpful; the education is clear. The information is understandable." (P1, P3) |
|                                                                                    | 5.2 Community-based support       | (21) Health cadre home visits<br>(22) Presence of posyandu lansia in the residential area                        | "If my husband cannot come to the health post, the cadre comes to our home." (P3)                           |

### Theme 1: Understanding of Diabetes Based on Patient Symptoms and Causes

All participants described DM as the "sugar disease" based on local terminology. The blood glucose readings of all patients under their care were above 200 mg/dL at first diagnosis. The symptoms identified included gastrointestinal disturbances (nausea, vomiting), polyuria, polydipsia, drowsiness, and limb disturbances (numbness, herpes-like wounds).

"We found out during a trip to Banjaran; my mother kept vomiting on the road, then fainted, and was taken

to RS Muhammadiyah. When examined, her blood sugar turned out to be 480." (P1)

"Her blood sugar reached 350 at the time, and she was hospitalized at RS Pindad for 16 days; she was even suspected of having COVID because she was placed in an isolation room." (P3)

The causes of DM understood by the participants were dominated by dietary patterns high in sugar and simple carbohydrates, as well as a lack of physical activity. A small number of

participants did not know the exact cause of DM. Regarding complications, several participants mentioned cardiac, ocular, and neurological disorders, while others stated that they were unaware of DM complications.

*"The cause is from food, like rice. Now I give her brown rice, but her blood sugar after meals is still high." (P3)*

## **Theme 2: Home-Based Care Efforts for Patients with DM**

Caregivers carried out five dimensions of self-care at home: (1) medication reminders, (2) monitoring and regulating dietary patterns, (3) physical-activity reminders (walking, sunbathing), (4) periodic inspection of foot wounds, and (5) management of emergency conditions. Caregivers perceived themselves as contributing to patients' adherence to the treatment program and to routine visits to the primary health center through reminders, accompaniment, and direct administration of medication.

*"I often remind her to eat, not carelessly. I am the one who gives the medication: morning, noon, and before bed. My husband also likes to take morning walks and sunbathe." (P3)*

*"She has never missed a visit to the primary health center. No matter how dizzy or how much her heart races, she still goes to the health center." (P1)*

All participants reported that there were currently no open wounds on the patients. In emergency conditions (extreme hyperglycemia), all participants immediately took the patient to the hospital emergency department.

*"We took him straight to the hospital. His foot looked like red herpes, wounded but not blistered, as if burned. He was in the ICU for three days." (P5)*

## **Theme 3: Barriers Experienced by Caregivers**

Most participants stated that they had no meaningful barriers in carrying out the caregiver role. The patient's relatively independent physical condition and the established routines served as protective factors. Nevertheless, some participants expressed psychological barriers in the form of fatigue and emotional stress.

*"There is fatigue. But what can I do? Caring for the sick requires strength. If I cannot do it, then who else would care for him?" (P3)*

*"Yes, sometimes I get annoyed, even angry. But I just treat it as worship, simply helping one another." (P5)*

Social barriers were rarely reported; most participants were still able to take part in community activities such as religious gatherings and communal work. Economic barriers were not categorized as a heavy burden because all patients were registered as members of the National Health Insurance (BPJS Kesehatan).

## **Theme 4: Motivation for Caring for Patients with DM: Devotion and Affection**

Three main dimensions of motivation drove caregivers to perform their roles: (1) obligation based on the family role (husband, wife, or child), (2) a sense of affection and mutual care, and (3) spiritual values (caring as an act of worship). These three dimensions mutually reinforced one another and shaped caregiver resilience in facing the challenges of long-term care.

*"Caring is a wife's duty when her husband is ill. Who else would care for him while his wife is still around?" (P3)*

*"If my mother is ill, then I, as her child, am certainly obligated to care for her. It is our duty as children." (P4)*

*"I simply treat it as worship. We just help one another now that we are old." (P5)*

*"If the wife is ill, the husband provides care. If the husband is ill, the wife provides care. We look after and care for one another." (P2)*

## **Theme 5: Ease of Obtaining DM Care Information from Health Workers**

All participants stated that the information obtained from health workers at the primary health center through Prolanis activities was very helpful and easily understood. The friendly attitude of the health workers increased the participants' comfort in accessing services. The presence of the elderly health post (posyandu lansia) and health cadres in their residential area was also perceived as beneficial, particularly for patients with limited mobility.

*"The primary health center is helpful; the education is clear. The information is understandable." (P1, P3)*

*"If my husband cannot come to the health post, the cadre comes to our home." (P3)*

*"The information is very helpful; they are friendly and make us comfortable." (P5)*

### **The Essential Structure of the Caregiving Experience**

By integrating the five themes in the final steps of Colaizzi's analysis, the essential structure of the family caregiving experience could be formulated as follows. For these caregivers, caring for a family member with DM was not experienced as a chosen task but as a taken-for-granted moral obligation embedded in their family role. The disease first entered their awareness through the body of the patient, through sudden and frightening events such as fainting, vomiting, or hospitalization, rather than through biomedical knowledge; consequently, their understanding of DM remained grounded in lived proximity to symptoms rather than in conceptual knowledge of the disease. Day-to-day care took the form of continuous, embodied watchfulness over medication, meals, physical activity, and the skin and limbs of the patient. The burden of this watchfulness was real, felt as fatigue and moments of anger, yet it was absorbed rather than voiced, because it was made meaningful by affection, by the reciprocity of marital and filial duty, and, above all, by the understanding of caregiving as an act of worship. Within this horizon, accessible, friendly, and trusted information from Prolanis health workers and community cadres was experienced not merely as a service but as reassurance that the caregiver was not alone. The essence of the experience is therefore caregiving as quiet devotion: an unconditional act of love and worship, sustained by family obligation and supported by trusted primary health services, through which caregivers preserve the dignity and everyday life of the person they care for.

### **Discussion**

Taken together, the findings portray family caregiving in DM not as a set of tasks but as a meaningful whole, an experience that the

caregivers themselves interpreted through the lenses of obligation, affection, and worship. The following discussion relates each dimension of this experience to previous studies.

### **Caregivers' Understanding of Diabetes Mellitus**

The findings indicate that caregivers' understanding of DM remained predominantly at the level of empirical experience and was insufficient regarding complications and pathophysiology. This is consistent with the study by Sofwan (2024), which found that families tend to understand DM from visible clinical manifestations rather than from conceptual understanding. Tarigan et al. (2025), in a qualitative study of 12 family members of patients with type 2 DM in Medan, also reported that family understanding was influenced by health literacy and access to information from health workers.

The knowledge gap regarding DM complications is an important concern from a family nursing perspective. Saltar et al. (2025), in a phenomenological study of patients with DM and neuropathy in Indonesia, found that limited knowledge of DM management was a major barrier to self-care. Structured education involving caregivers has been shown to improve family understanding and self-management capacity (Harahap et al., 2025).

### **Caregivers' Home-Based Care Efforts**

The five dimensions of care performed by caregivers reflect the practical implementation of family health tasks (Friedman, 2014) and are consistent with the five pillars of DM management according to PERKENI (Perkumpulan Endokrinologi Indonesia, 2021), namely education, medical nutrition therapy, physical exercise, pharmacological therapy, and blood glucose monitoring. Caregivers had naturally internalized these roles even without formal training.

The high level of patient adherence in this study is consistent with the active role of caregivers as reminders. Utami and Mariana (2025) reported a meaningful relationship between family support and adherence to routine check-ups among patients with DM ( $p=0.002$ ). A literature review by Setyoadi et al. (2024) concluded that caregivers' lack of knowledge and skills constitutes a risk factor for caregiver burden, which affects the quality of care for patients with type 2 DM.

### Caregiver Barriers

The psychological barrier of fatigue reported by some participants is consistent with the review by Siregar et al. (2025), which stated that the quality of life of caregivers of elderly patients with DM in Indonesia is influenced by depressive symptoms and caregiver burden. Josefin et al. (2025) also found a correlation between burden and the quality of life of informal caregivers of elderly patients with DM. Overall, the participants' capacity to continue their caregiving role despite fatigue appeared to be supported by spiritual motivation and social support from the community, although resilience was not formally measured as an analytic concept in this study.

### Caregiving Motivation: Perspectives of Obligation, Affection, and Spirituality

Among participants in this study, caregiving motivation appeared to be embedded in family obligation, affection, and religious or spiritual values. This pattern is consistent with the cultural and spiritual context of the study setting, which is grounded in religious values and the kinship system. This motivation is a source of strength that can be mobilized in family-based interventions. The Family-Centered Empowerment Model (FCEM) developed by Alzawahreh and Ozturk (2024) has been shown to improve self-efficacy, quality of life, and HbA1c control by actively involving the family. Rozana et al. (2025) demonstrated that the FCEM intervention significantly improved the resilience of caregivers of patients with type 2 DM ( $p=0.000$ ,  $t=13.644$ ).

### Access to Information and the Role of Health Workers

The positive assessment by all participants of the quality of information from Prolanis indicates that the service has functioned as an effective primary source of education. The role of community health cadres in home visits strengthens the care support system beyond health facilities. Hidayat et al. (2025) reported that empowering cadres and families through foot exercises and traditional medicinal plants was able to improve DM management in the community. The digitalization of FCEM through digital-based applications also shows great potential for improving the quality of education and the empowerment of DM caregivers (Wildana et al., 2024).

### Conclusions

This phenomenological study identified five essential themes of family caregivers' experiences in caring for patients with DM: (1) understanding of DM based on empirical experience that remains limited regarding complications; (2) comprehensive home-based care efforts encompassing medication monitoring, diet, activity, and emergency management; (3) psychological barriers in the form of fatigue that are addressed through sound resilience; (4) motivation derived from family obligation, affection, and spiritual values; and (5) a positive assessment of the ease of access to information from health workers and community cadres. The essential structure of the experience was formulated as caregiving as quiet devotion: an unconditional act of love and worship, sustained by family obligation and supported by trusted primary health services.

Based on these findings, it is recommended that: (1) primary health centers develop structured and continuous caregiver education programs that focus not only on patients but also on caregivers' competence in recognizing complications; (2) the Family-Centered Empowerment Model (FCEM) be implemented as a family nursing intervention; (3) Prolanis coordinators integrate understanding assessments into digital education programs; and (4) further research employ interventional designs to test the effectiveness of structured education programs for DM caregivers in the community.

### Ethical Statement

This study received ethical approval from the Research Ethics Committee Universitas Aisyiyah Bandung No:1309/KEP. 01/UNISA-BANDUNG/VI/2025 date of 6 Juni 2025 All participants signed written informed consent. Participant identities were kept confidential using the codes P1-P6.

### Conflict Of Interest

The authors declare that there is no conflict of interest in this study.

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including the funding statement, is provided on the separate title page file.

## References

- Alzawahreh, S., & Ozturk, C. (2024). Improving self-efficacy, quality of life, and glycemic control in adolescents with type 1 diabetes: Randomized controlled trial for the evaluation of the family-centered empowerment model. *JMIR Formative Research*, 8, e64463. <https://doi.org/10.2196/64463>
- Ananda, H. S., Jamiat, N., & Gunawan, H. (2020). Relationship between family support and activeness of Prolanis participants with diabetes mellitus. In *Proceedings of the 1st International Conference on Science, Health, Economics, Education and Technology (ICoSHEET 2019)*. Atlantis Press. <https://doi.org/10.2991/ahsr.k.200723.051>
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). SAGE Publications.
- Dinas Kesehatan Kota Bandung. (2022). *Profil kesehatan Kota Bandung tahun 2022*. Dinas Kesehatan Kota Bandung.
- Friedman, M. M. (2014). *Buku ajar keperawatan keluarga: Riset, teori, dan praktik*. EGC.
- Harahap, S., Tarigan, M., Nasution, S. Z., & Tanjung, M. S. (2025). Perspektif keluarga tentang praktik manajemen diri diabetes: Sebuah studi kualitatif [Family perspectives on diabetes self-management practices: A qualitative study]. *Jurnal Ners*, 9(3), 4512-4518. <https://doi.org/10.31004/jn.v9i3.46877>
- Hidayat, A., Adrianur, F., & Badar, B. (2025). Pemberdayaan kader dan keluarga: Pengelolaan diabetes melalui senam kaki dan tanaman obat tradisional [Empowering cadres and families: Diabetes management through foot exercises and traditional medicinal plants]. *GEMAKES: Jurnal Pengabdian Kepada Masyarakat*, 5(1), 82-88. <https://doi.org/10.36082/gemakes.v5i1.1928>
- International Diabetes Federation. (2021). *IDF diabetes atlas* (10th ed.). <https://www.diabetesatlas.org>
- Jamiat, N., & Salami, W. S. (2024). *Laporan penelitian hibah internal [Internal research grant report]*. Universitas Aisyiyah Bandung.
- Josefin, J. M., Debora, O., Ati, M. P. P., & Sipollo, B. V. (2025). Hubungan beban dengan kualitas hidup caregiver informal yang merawat lansia penderita diabetes melitus. *Jurnal Ilmiah Keperawatan (Scientific Journal of Nursing)*, 11(3), 522-530. <https://doi.org/10.33023/jikep.v11i3.2797>
- Kementerian Kesehatan Republik Indonesia. (2023). *Survei kesehatan Indonesia 2023*. Badan Kebijakan Pembangunan Kesehatan, Kementerian Kesehatan RI.
- Perkumpulan Endokrinologi Indonesia. (2021). *Pedoman pengelolaan dan pencegahan diabetes melitus tipe 2 dewasa di Indonesia 2021*. PB PERKENI.
- Rozana, A. A., Rondhianto, R., & A'la, M. Z. (2025). Effect of family caregiver empowerment model intervention on resilience in caregivers of type 2 diabetes mellitus patients. *Jurnal Kesehatan dr. Soebandi*, 13(2), 237-245. <https://doi.org/10.36858/jkds.v13i2.784>
- Saltar, L., Sahar, J., Rekawati, E., & Ayubi, D. (2025). A phenomenological exploration of the lived experiences and self-management challenges among patients with type 2 diabetes living with neuropathy in Indonesia. *Journal of Holistic Nursing Science*, 12(2), 214-227. <https://doi.org/10.31603/jhns.v12i2.13492>
- Setyoadi, S., Meiliana, S. W., Hakim, F. O., Hayati, Y. S., Kristianingrum, N. D., Kartika, A. W., & Sandi, P. S. (2024). The burden of family caregivers in the care of type 2 diabetes mellitus patients: A literature review. *Journal of Rural Community Nursing Practice*, 2(1), 40-47. <https://doi.org/10.58545/jrcnp.v2i1.207>
- Siregar, R., Kritpracha, C., Chinnawong, T., & Latour, J. M. (2025). Quality of life among Indonesian family caregivers caring for dependent older persons with type 2 diabetes mellitus in the community: A cross-sectional, correlational study. *Belitung Nursing Journal*, 11(1), 48-58. <https://doi.org/10.33546/bnj.3683>
- Sofwan, S. (2024). Studi fenomenologi pengalaman keluarga dalam merawat lansia dengan diabetes mellitus [A phenomenological study of family experiences in caring for elderly people with diabetes mellitus]. *Antigen: Jurnal Kesehatan Masyarakat dan Ilmu Gizi*, 2(1), 140-151. <https://doi.org/10.57213/antigen.v2i1.237>



- Tarigan, M., Harahap, S., Nasution, S. Z., Bukit, E. K., Lindarto, D., & Silaban, D. F. (2025). Family experience in supporting diabetes self-management practice: A qualitative study. *Caring: Indonesian Journal of Nursing Science*, 7(2), 259-268. <https://doi.org/10.32734/ijns.v7i2.23251>
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357. <https://doi.org/10.1093/intqhc/mzm042>
- Utami, L., & Mariana, R. (2025). Hubungan dukungan keluarga dengan kepatuhan kontrol rutin penderita diabetes melitus [The relationship between family support and routine control adherence in patients with diabetes mellitus]. *JoIN: Journal of Intan Nursing*, 4(1), 22-28. <https://doi.org/10.54004/join.v4i1.287>
- Wildana, F., Lutfian, L., Azizah, A., Wardika, I. J., Ramadhani, F. B., & Utomo, W. D. (2024). The effectiveness of digitalization in family caregiver empowerment model (FCEM) for reducing diabetes incidence in rural areas: An app-based literature review study. *Journal of Health Sciences*, 17(3), 297-307. <https://doi.org/10.33086/jhs.v17i03.5620>